

DOCUMENT RESUME

ED 330 135

EC 300 105

TITLE Commonwealth of Virginia: Board for Rights of the Disabled. 1990 Report.

INSTITUTION Virginia State Board for Rights of Virginians with Disabilities, Richmond.

PUB DATE 1 Jan 90

NOTE 67p.; For appendices A and B and Synopsis, see EC 300 106-108.

PUB TYPE Reports - Evaluative/Feasibility (142)

EDRS PRICE MF01/PC03 Plus Postage.

DESCRIPTORS Adults; Advocacy; Attitudes; Children; Community Services; *Developmental Disabilities; *Disabilities; Employment; Employment Opportunities; Financial Needs; Individual Needs; *Needs Assessment; Normalization (Handicapped); Personal Autonomy; Productivity; *Quality of Life; Social Integration; Special Education; *State Programs; State Surveys; Statewide Planning

IDENTIFIERS *Developmental Disabled Assist Bill of Rights Act; *Virginia

ABSTRACT

This report responds to requirements of Public Law 100-146, The Developmental Disabilities Assistance and Bill of Rights Act Amendments of 1987. It describes existing services to persons with developmental disabilities, reports on a consumer satisfaction survey, and presents recommendations and plans. Thirteen major findings and discussion of 16 critical issues in Virginia are presented in six sections. Many people with developmental disabilities have no access to services; services and supports related to financial welfare dominate perceptions of satisfaction and need; and the social support networks of most consumers are extremely limited. Critical issues are discussed within the categories of education, employment, community living, and unserved/underserved constituencies. These issues include: (1) a lack of consensus regarding federal and state standards for special education and insufficient mechanisms for monitoring compliance; (2) insufficient and inadequate services and supports to permit remunerative employment; (3) a lack of effective case management services; and (4) a lack of documentation concerning numbers and service needs of persons with developmental disabilities. The final section presents implementation and advocacy plans for the Board for Rights of the Disabled which are intended to consolidate the disparate mandates and activities of the past and build a unified coalition of individuals and organizations to advocate for the developmentally disabled. (DB)

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**COMMONWEALTH OF VIRGINIA
BOARD FOR RIGHTS OF THE DISABLED**

1990 REPORT

**As required by Public Law 100-146
"The Developmental Disabilities Assistance and
Bill of Rights Act Amendments of 1987"**

January 1, 1990

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PREFACE

The report you are about to read is not fundamentally about services or money. It is about people and about values articulated over 200 years ago in this Commonwealth. It is about Virginians for whom Thomas Jefferson's vision of the individual right to life, liberty, and the pursuit of happiness is not a reality.

This happens solely because of physical or mental differences that accentuate the individuality of these persons, the very individuality which is prized and protected in those basic charters of our nation which were written by Virginians.

As originators of this report, we must acknowledge that we were not aware of the extent of shadow facing persons with developmental disabilities. If you do not have a developmental disability, you probably did not know either. We still don't. We don't face the day-to-day demands of living within a society that is mostly indifferent. Yet, through this survey and report a small window of vision has been opened. We can begin to see and understand what it means to have a developmental disability.

Relative to persons without a disability,

- o most persons with a developmental disability are alone,
- o they are poor,
- o they are uninvolved, standing on the periphery of life,
- o they are told what to do,
- o they are unproductive, and
- o they are treated without respect and dignity.

Each Virginian has a different reaction to these facts. Some are angry; others are sad. Many feel helpless and others feel frustrated. Some deny the existence of these citizens Virginians and their plight. For this last group, it is our hope that you will never be able to deny it again after reading this document. For all, we wish the understanding that we should help and the confidence that we can help.

For it is our fervent belief that lives of shadow can be transformed, not in the twinkling of an eye, but with the dedicated work of many minds, hearts, and hands. There is job enough for all. Let us continue.

1990 REPORT

EXECUTIVE SUMMARY

EXECUTIVE SUMMARY

SECTION I

1990 REPORT: BACKGROUND AND PROCESS

In Virginia, one of the major responsibilities of the Board for Rights of the Disabled is to serve as the "State Planning Council" for Virginians with developmental disabilities. Developmental disabilities result from severe mental and/or physical impairments which begin at an early age, which are likely to continue indefinitely or lifelong, which have a pervasive limiting effect on an individual's functional abilities, and which create need for a variety of continuing services and supports.

PUBLIC LAW 100-146, "The Developmental Disabilities Assistance and Bill of Rights Act Amendments of 1987", includes extensive new study/reporting requirements for each state. It requires that a comprehensive, multifaceted **1990 REPORT** be developed by each "State Planning Council" for submission to the Governor and State Legislature by January 1, 1990, followed by submission to the Administration on Developmental Disabilities by January 15, 1990.

The **1990 REPORT** must include:

- 1) Description of "eligibility for, extent, scope, and effectiveness" of services provided to persons with developmental disabilities by relevant Federally-assisted and State-funded programs
- 2) Findings from a "Consumer Satisfaction Survey", which minimally must include a representative sample of clients of relevant Federally-assisted programs and persons with all types of developmental disabilities
- 3) Recommendations for how the State will address unserved/underserved constituencies of persons with developmental disabilities, including designation of responsible agency/agencies to provide and coordinate needed services
- 4) Plans for how the "State Planning Council" will incorporate the **1990 REPORT** findings into its ongoing systems advocacy role to promote public policy, consumer empowerment, and model service demonstrations to benefit persons with developmental disabilities and their families

The **1990 REPORT** will provide direction in Virginia for establishing appropriate policies and effective service delivery that will enhance the independence, productivity, and community integration of persons with developmental disabilities. Following submission of a **1990 REPORT** by every state, the U.S. Department of Health and Human Services will submit a composite report to Congress which is expected to influence future Federal legislation, budgets, and administration of programs which affect persons with developmental disabilities.

Since its inception, the concept of developmental disabilities reflected in Federal legislation has evolved from a categorical approach to a functional approach. The Federal definition of **"developmental disability"** contained in Public Law 100-146 designates criteria of early onset, severity of impairment(s), multiple functional limitations, chronicity, and need for a variety of individualized, coordinated services that are long-term or lifelong. All of these criteria can be difficult to consistently interpret or to operationalize. The intent of the federal Developmental Disabilities Act is to focus attention for comprehensive planning and policy development, particularly to benefit unserved and underserved constituencies.

As specified in Public Law 100-146, **Independence** means the extent to which a person with developmental disabilities exerts control and choice over his/her own life. **Productivity** means the engagement of a person with developmental disabilities in income-producing work which is measured through improvements in income level, employment status, job advancement or contribution to a household or community. **Integration** means the involvement of people with developmental disabilities in: a) the use of the same community resources and participation in the same community activities that are available and used by other citizens; b) living in a home or home-like setting which is in close proximity to community resources; and c) having regular contact with nondisabled citizens in their community.

Currently no single State or local agency is responsible for serving persons with developmental disabilities. Local Education Authorities are responsible to provide or obtain appropriate special education and related services needed by eligible children with developmental disabilities. Persons whose primary impairment is moderate or severe mental retardation and/or mental illness or who have a substance abuse problem are under the auspices of the Department of Mental Health, Mental Retardation and Substance Abuse Services, and local Community Services Boards. Persons with developmental disabilities who are primarily physically handicapped or who have sensory impairments may receive various special services through such agencies (and their local units) as the Department of Rehabilitative Services, the Department for the Visually Handicapped, and the Department for the Deaf and Hard of Hearing. Persons with developmental disabilities also may be eligible to receive generic services available from such agencies as the Department of Health, the Department of Medical Assistance Services, the Department of Social Services, and the Virginia Employment Commission. At the local level, persons with developmental disabilities must seek assistance from a number of public and private agencies.

In particular, there are several Federally-assisted state programs which offer, or potentially offer, services to Virginia's population with developmental disabilities. These public programs are the most significant resources for persons with developmental disabilities, although not designated specifically for this population. With few exceptions, specific data related to extent or level of services provided to the developmentally disabled are unavailable. The Federally-assisted programs are organized in various ways to deliver their services, based upon their statutory and administrative requirements. As such, they are not presently organized into a comprehensive, coordinated service delivery system. Separate eligibility criteria and service networks have been established. These programs may support local or regional activities which may operate as subunits of State agencies, as agencies of local government, or by contractual arrangements with independent agencies.

In its role as the "State Planning Council" under Public Law 100-146, the Board for Rights of the Disabled is mandated to promote coordinated planning, evaluation, and delivery of services to persons with developmental disabilities. Its purpose is to stimulate the service delivery system to be more responsive, effective, and efficient. The Council acts as a systems advocate to attempt to influence at the policy and political level.

SECTION II

SUMMARY OF FINDINGS FROM THE ANALYSIS OF FEDERALLY-ASSISTED AND STATE FUNDED PROGRAMS SERVING INDIVIDUALS WITH DEVELOPMENTAL DISABILITIES IN VIRGINIA

- o Large groups of people with developmental disabilities have no access to services.
- o Not all individuals with developmental disabilities in Virginia have equal access to needed services. Availability of critical services varies widely from community to community.
- o Virginia has not moved rapidly enough to implement the concept of least restrictive environment as a guiding principle of its service delivery system and relies much too heavily on program alternatives that are neither appropriate nor cost-effective.
- o Virginia makes few efforts to systematically evaluate the effectiveness and efficiency of services and supports provided to individuals with developmental disabilities. Despite efforts of the Board for Rights of the Disabled, opportunities for consumers and families to express satisfaction and concern with the services they receive are rarely provided.

SECTION III

SUMMARY OF FINDINGS FROM THE VIRGINIA CONSUMER SATISFACTION SURVEY

- o Consumers with developmental disabilities are dissatisfied with sitting on the sidelines of life. They want the services and supports that will allow them to be active and integrated members of their communities.
- o Services and supports related to financial welfare dominate perceptions of satisfaction and need.
- o While satisfaction with Virginia's direct services is generally high, satisfaction with supports (that are often needed to use services effectively) is much lower.
- o Virginia's service delivery system often fails to target its resources with appropriate differentiation across disability groups.
- o The unavailability of work is a major barrier to increasing productivity and quality of life for many persons with developmental disabilities.
- o The social support networks of most consumers are extremely limited.
- o Virginia's commitment to the independence of persons with developmental disabilities is often limited by the vested interests of primary caregivers and service delivery systems.
- o While children and their parents are generally satisfied with their current service and family environments, this satisfaction often cloaks dependence, a potential barrier of importance to future life satisfaction.
- o Many consumers remain isolated and limited in their involvement in "real world" roles and environments.

SECTION IV
EDUCATION: SUMMARY OF CRITICAL ISSUES

- o Lack of consensus regarding Federal and State standards for special education and insufficient/inadequate mechanisms for monitoring compliance
- o Insufficient numbers of appropriately trained educators, administrators, and related services personnel
- o Students with developmental disabilities are exiting schools (e.g. aging-out) without the skills or experience necessary to maximize their current or future independence, productivity, and integration into community life
- o The majority of students with developmental disabilities are regularly denied access to and experience with age-appropriate peers who are not handicapped

SECTION V
EMPLOYMENT: SUMMARY OF CRITICAL ISSUES

- o Insufficient and inadequate services and supports to permit remunerative employment
- o Inadequate efforts to communicate the ability and availability of persons with developmental disabilities to engage in meaningful and productive employment
- o Empowerment of consumers with developmental disabilities to have options and make choices regarding employment

SECTION VI
COMMUNITY LIVING: SUMMARY OF CRITICAL ISSUES

- o Consumer empowerment for community living
- o Insufficient and inadequate community services and supports
- o Lack of effective case management services
- o Lack of accessible/affordable transportation

SECTION VII
**UNSERVED/UNDERSERVED CONSTITUENCIES WITH DEVELOPMENTAL DISABILITIES:
SUMMARY OF CRITICAL ISSUES**

- o Inequities among constituencies with developmental disabilities
- o Lack of documentation concerning numbers and service needs of persons with developmental disabilities
- o Lack of sufficient and appropriate human services in Virginia and interagency limitations
- o Lack of designation and enforcement of agency responsibility for all persons with developmental disabilities
- o Inadequate funding

1990 REPORT RECOMMENDATIONS

The Board for Rights of the Disabled makes the following recommendations to address the identified critical issues concerning unserved/underserved constituencies with developmental disabilities and the barriers to service delivery and opportunities which would promote optimal independence, productivity, and community integration of all individuals with developmental disabilities.

EDUCATION

APPROPRIATE PROGRAMS AND SERVICES

1. The Department of Education should enforce implementation of "Standards of Quality" for the delivery of special education and related services by Local Education Authorities. Persons with developmental disabilities, parents and other family members, and disability advocacy organizations should have active participation through public comment opportunities and the legislative process in future revisions of these "Standards of Quality".
2. The Department of Education should aggressively monitor and follow through with implementation of corrective action plans with Local Education Authorities to insure uniform compliance with the intent and requirements of P.L. 94-142.
3. The Department of Education should implement policies and regulations to insure that all children and youth with developmental disabilities are educated to the maximum extent possible and appropriate with non-disabled peers and within their home communities. A full range of appropriate placement options should be available.
4. The Department of Education should increase its efforts to assure the employment of sufficient numbers of appropriately trained/certified special education teachers and related services personnel by Local Education Authorities. Local Education Authorities should employ additional personnel (e.g. psychologists, social workers, guidance counselors, physical therapists, speech pathologists, occupational therapists, audiologists, interpreters, etc.) and other providers of related services.
5. The Department of Education should provide technical assistance necessary to assure that educational standards and regulations are appropriately implemented. Particular areas needing attention are academic and functional curricula, assistive technology, vocational training, and leisure skills training. These areas should be directly reflected in Individual Education Plans for children and youth with developmental disabilities.
6. The Department of Education should establish, monitor, and enforce favorable caseload standards to assure that the needs of children and youth with developmental disabilities are met with appropriate special education and related services.

PERSONNEL PREPARATION

7. The Department of Education should strengthen its policies and procedures for the certification/re-certification of teachers, administrators, and other educational personnel to address the appropriate preparation of both "special education and related services" personnel and "regular education" personnel to work effectively with children and youth with developmental disabilities. Local Education Authorities should aggressively work to recruit and employ qualified personnel with disabilities.

8. The Department of Education should establish specific certification categories for teachers qualified to teach children and youth with **autism**, children and youth with **traumatic brain injury**, and children and youth who are **multihandicapped**. Teacher preparation programs in these areas must be established.
9. The Secretary of Education and the State Council on Higher Education should direct Virginia's institutions of higher education to expand and initiate new programs of appropriate education and preservice training for teachers and related personnel to become qualified/certified to provide special education and related services needed by children and youth with developmental disabilities.

PRESCHOOL AND POSTSCHOOL TRANSITION

10. The General Assembly should establish funding specifically to promote a comprehensive, coordinated system of services for children ages 0-2 years with developmental delay or those with a diagnosed condition or subject to environmental factors which have a high probability of resulting in delay. This should promote the collaborative efforts of community agencies, including Local Education Authorities, to comply with Public Law 99-457, Part H in the provision of early intervention and transition services for infants and toddlers.
11. The General Assembly should require and provide funding for a formal statewide transition effort to promote collaborative activities between school divisions and community service agencies to provide for transition planning and delivery of transition services for youth with developmental disabilities who are exiting school and entering adult community life.

EMPLOYMENT

1. The General Assembly should provide sufficient permanent funding to expand and maintain long-term supported employment opportunities for persons with severe physical, sensory, and/or mental disabilities. This should include funding to provide for appropriately trained personnel necessary for supported employment activities.
2. The General Assembly should provide incentive funding to encourage rehabilitation facilities and sheltered workshops to develop and expand community supported employment opportunities.
3. The General Assembly should mandate the implementation of a coordinated, interagency job-matching placement and follow-along system for persons with disabilities. This system should include the collaborative efforts and participation of all appropriate publically-supported State and local agencies and programs.
4. The General Assembly should provide funding for a voucher system to provide needed ancillary support services (e.g. transportation; procurement of adaptive equipment, mobility aids, or communication devices; child care; etc) to allow employment and promote the independence of individuals with developmental disabilities.
5. The General Assembly should create State tax incentives which will benefit employers who hire and provide long-term supports which allow persons with developmental disabilities to maintain remunerative employment.

6. Local Education Authorities and community agencies should work collaboratively with the Department of Education using "Virginia's Plan of Coordinated Transitional Services for Youth and Young Adults with Disabilities" to educate students with developmental disabilities, family members, employers, and the public concerning the employment potential of individuals with developmental disabilities.
7. The General Assembly should mandate the Secretary of Administration and the Department of Personnel and Training to strengthen Virginia's commitment to affirmative action in hiring and promoting persons with disabilities within all areas of State government through explicit directives, education, and monitoring.

COMMUNITY LIVING

CONSUMERISM

1. The Governor should promote and monitor self-advocacy and consumer empowerment in all public agencies by requiring through an Executive Directive that there be continuous consumer participation in decisions concerning the planning and implementation of services for individuals with disabilities.
2. The General Assembly should establish and make uniformly available throughout the State a system of case management services for persons with developmental disabilities that is **independent from agencies which directly fund/provide services**. Case load sizes should be limited to 20-40 persons to allow individualized, consumer-directed services.
3. The General Assembly should establish and make uniformly available throughout the State a Quality Assurance System that is **independent from agencies which directly fund/provide services**, that actively involves consumers with developmental disabilities and their families, and which evaluates programs and services with criteria of individual outcomes relating to independence, productivity, and community integration.
4. The Department for Rights of the Disabled should collaborate with Centers for Independent Living and disability advocacy organizations to sensitize/educate health care personnel in appropriate interaction with persons with developmental disabilities and their families and in the use of existing information and referral services which will assist them.

INCREASED SERVICES AND SUPPORTS

5. The General Assembly should require the Department of Medical Assistance Services to work collaboratively with appropriate State and local agencies to determine the feasibility of expanding the scope and increasing the individuals eligible to participate in all aspects of the Medicaid program, particularly to increase opportunities for community-based habilitation/rehabilitation services needed by persons with developmental disabilities.
6. The General Assembly should provide permanent funding to significantly expand and make uniformly available **supported employment services, independent living services, and rehabilitation engineering/assistive technology services**. The administration and implementation of these services should be coordinated among DRS, CILs, DMHMRSAS, CSBs, and other appropriate state and local agencies.

7. The General Assembly should require and provide funding to establish and make uniformly available a statewide Personal Assistance Services (PAS) system of consumer-directed, individualized supports necessary to promote the maximum independence and productivity of individuals with developmental disabilities. This system would provide attendant services to assist in accomplishing activities of daily living; it would include financial/technical assistance to obtain adaptive equipment, communication devices, and mobility aids which maximize individual functioning.
8. The General Assembly should establish State tax credits/tax deductions for families or individuals who provide a home and supervision/care for family members or other persons with developmental disabilities, if such living arrangement and care represents the "least restrictive environment" available during the applicable tax year.
9. The General Assembly should require and provide funding to establish a multifaceted system of Family Support Services (FSS) to be uniformly available throughout the state for all persons with developmental disabilities. This flexible system would respond to changing individualized needs of families; it would include direct support services, stipends/vouchers to purchase or obtain services, and financial/technical resources to obtain adaptive equipment, communication devices, and mobility aids which maximize individual functioning.
10. The General Assembly should support the establishment and maintenance of local or regional Family Support Resource Centers throughout the state. These would provide centralized information about and referral to local and regional programs and services for persons with developmental disabilities, planning and problem-solving consultations, counseling and specialized training for family members and/or primary caregivers, and respite services.

HOUSING

11. The Board of Housing and Community Development should insure compliance with the federal Fair Housing Amendments Act of 1988 through the Uniform Statewide Building Code. Enforcement of the Act's adaptability and accessibility requirements should receive high priority from the Department of Housing and Community Development, and continuing education and training should be provided to building designers and inspectors.
12. The General Assembly should establish and fund a rental assistance program for persons with disabilities who meet low income criteria.
13. Agencies of State government that provide housing and other services to persons with disabilities and disability advocacy organizations should work collaboratively with the housing industry to make residences and appropriate support services, including personal assistance, available to people with disabilities.
14. The Department of Housing and Community Development should expand financial and technical assistance for modifying existing housing units to increase accessible housing opportunities for persons with disabilities.

TRANSPORTATION

15. The General Assembly should provide incentive funding for localities to promote purchase of lift-equipped buses and to encourage continuation and expansion of other transit services which promote mobility and independence for Virginians with disabilities. In addition, uniform equipment standards should be required by the Department of Transportation.

16. The General Assembly should require that formal transportation coordination agreements be developed and implemented among local providers of transportation services, especially in rural areas.
17. The Department of Transportation should provide funding to develop and implement an ongoing program of training for users who have disabilities and providers who serve persons with disabilities in public transportation systems.
18. The General Assembly should establish and fund a voucher program to allow individuals with developmental disabilities to obtain transportation services needed to work, to receive services, to perform daily activities, or to participate in community activities.

PERSONNEL PREPARATION

19. The Secretary of Education and the State Council on Higher Education should direct Virginia's institutions of higher education to expand and initiate new programs of preservice, interdisciplinary training to prepare professionals and paraprofessionals to deal with the assessment, training, and other service delivery needs of persons with developmental disabilities.
20. The General Assembly should require and provide funding for a statewide system of personnel support which includes inservice training and programmatic technical assistance for professionals and paraprofessionals who participate in the public/private developmental disabilities service delivery network.

PREVENTION

21. The General Assembly should require and promote implementation of primary, secondary, and tertiary prevention strategies to minimize the occurrence of medical conditions or mental/physical impairments which may result in developmental disabilities.

UNSERVED/UNDERSERVED CONSTITUENCIES WITH DEVELOPMENTAL DISABILITIES

1. The Secretary of Health and Human Resources and the Board for Rights of the Disabled should identify and address through the PLAN OF COOPERATION the service needs of constituencies with developmental disabilities who are currently unserved/underserved.
2. The General Assembly should authorize and provide funding for a legislative study to determine the agency/agencies responsible in Virginia to provide/coordinate comprehensive services for **all persons with developmental disabilities**, based upon the federal definition in the Developmental Disabilities Act.
3. The General Assembly should formally determine and enforce the ability and responsibility of all existing State and Federally-assisted agencies and programs to accommodate persons with developmental disabilities with appropriate services and supports. This may require formal interagency agreements initiated and enforced by the Secretary of Health and Human Resources and other cabinet Secretaries.

4. The General Assembly should provide sufficient funding and allocate appropriate manpower to enable significant growth in the human services system in Virginia. New specialized services and supports must be developed, financed, implemented, and monitored to meet the needs of Virginia's unserved/underserved population of persons with developmental disabilities. This may be accomplished both by expansion/modification of existing and traditional programs to accommodate persons with a variety of types of disabilities, and by creation of new appropriate programs and services needed by these constituencies.
5. The General Assembly should provide the Department of Rehabilitative Services with adequate funding/manpower to operationalize its legislative status as the State agency responsible to provide/coordinate services for persons with functional and central nervous system disabilities. This should coincide with the legislative mandate and funding for DRS to initiate and conduct a small pilot program of long-term rehabilitative case management services for persons with functional and central nervous system disabilities.
6. The General Assembly should require and provide funding for a coordinated statewide data base on disability to be established and maintained. This base of information must include extensive data about the characteristics and service needs of persons with disabilities, detailed information about relevant programs and services provided by state and local agencies, and employment information.
7. The General Assembly should require that all State and Federally-assisted programs in Virginia adopt and uniformly operationalize consistent definitions of services and eligibility criteria for disability programs.
8. The General Assembly should require all State and local agencies which receive public funds to establish and maintain waiting lists of people requesting services who are not being served or who desire additional services to provide data for planning, evaluation, and program development activities.

SECTION VIII

IMPLEMENTATION AND ADVOCACY PLANS FOR THE BOARD FOR RIGHTS OF THE DISABLED

The **1990 REPORT** and accompanying documents provide an overview of Virginia's present status, along with recommendations for actions which would promote full independence, productivity and community integration for all Virginians with developmental disabilities. The recommendations offer hope, specific direction, and some new consumer-directed ideas for maximizing the potential and improving the quality of life for persons with developmental disabilities.

It is important to remember that many of the **1990 REPORT** Recommendations are long term, "systems change" initiatives that can not occur overnight. The strategies proposed in this section incorporate a multi-tiered approach, including short and long range objectives. Traditional activities like interagency training and public education, as well as innovative approaches such as coalition building with non-disability related groups and media campaigns, are necessary. While strengthening grassroots support from both the disability and non-disability communities, the focus must also be to influence elected and appointed officials, including state agency heads and critical agency personnel.

SECTION I

**1990 REPORT:
BACKGROUND AND PROCESS**

1990 REPORT: BACKGROUND AND PROCESS

In Virginia, one of the major responsibilities of the Board for Rights of the Disabled is to serve as the "State Planning Council" for Virginians with developmental disabilities. Developmental disabilities result from severe mental and/or physical impairments which begin at an early age, which are likely to continue indefinitely or lifelong, which have a pervasive limiting effect on an individual's functional abilities, and which create need for a variety of continuing services and supports.

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A. BACKGROUND

The Federal Developmental Disabilities Act

In October, 1970, the Developmental Disabilities Services and Facilities Construction Act (Public Law 91-517) was enacted. The intent of that legislation was to recognize and address the needs of a specific segment of the handicapped population, persons with developmental disabilities, who have often been excluded from programs in the service delivery system of established human service agencies. For various reasons, including oversight, resistance, and lack of sufficient resources, the rights of persons with developmental disabilities to treatment and services have often been abrogated. Public Law 91-517 was amended in 1975 by the Developmentally Disabled Assistance and Bill of Rights Act (Public Law 94-103), in 1978 by the Rehabilitation, Comprehensive Services, Developmental Disabilities Amendment of 1978 (Public law 95-602), in 1984 by the Developmental Disabilities Act of 1984 (Public Law 98-527), and in 1987 by the Developmental Disabilities Assistance and Bill of Rights Act Amendments of 1987 (Public Law 100-146).

The overall purposes of the Developmental Disabilities Act as designated in Section 101(b) of Public Law 100-146 are:

"(1) to provide assistance to States and public and private nonprofit agencies and organizations to assure that all persons with developmental disabilities receive the services and other assistance and opportunities necessary to enable such persons to achieve their maximum potential through increased independence, productivity, and integration into the community;

"(2) to enhance the role of the family in assisting persons with developmental disabilities to achieve their maximum potential; and

"(3) to make grants to support a system in each State to protect the legal and human rights of persons with developmental disabilities."

With recent amendments, the Developmental Disabilities Act provides more than a statement of financial and programmatic requirements. It contains the basic policy foundation for planning, managing, and evaluating service delivery systems for persons with developmental disabilities. One of the primary and overriding goals embodied in the legislation is the identification of barriers that prevent persons with developmental disabilities from achieving their full potential in their communities, and the development of policies and programs at the national, state, and local levels which will help to remove those barriers. Important leadership roles are given to State Planning Councils, Protection and Advocacy Agencies, and University Affiliated Programs.

The **Developmental Disabilities Basic State Grant Program** is currently authorized under Part B of Public Law 100-146, "The Developmental Disabilities Assistance and Bill of Rights Act Amendments of 1987." Federal funds are allotted by the U.S. Department of Health and Human Services, Administration on Developmental Disabilities to a "Designated State Agency" to support the joint activities of an independent "State Planning Council" and the Designated State Agency to develop and implement an annual "Developmental Disabilities State Plan." Currently in Virginia, the **Department of Mental Health, Mental Retardation and Substance Abuse Services** is the "Designated State Agency" and the **Board for Rights of the Disabled** is the "State Planning Council."

The purpose of the Developmental Disabilities Basic State Grant Program in Virginia is to assure that persons substantially handicapped by developmental disabilities receive the treatment, care, programs, and services needed to thrive and attain an optimal level of independence. This can be achieved through the collective activities of public and private agencies and consumer organizations at the State and local levels. The Developmental Disabilities Basic State Grant Program provides a forum and a mechanism to promote the availability of a full array of appropriate services for persons with developmental disabilities. In its role as the "State Planning Council" under Public Law 100-146, the Board for Rights of the Disabled is mandated to promote coordinated planning, evaluation, and delivery of services to persons with developmental disabilities. Its purpose is to stimulate the service delivery system to be more responsive, effective, and efficient. The Council acts as a systems advocate to attempt to influence at the policy and political level.

The Basic State Grant Program in Virginia is currently subject to the approved **DEVELOPMENTAL DISABILITIES TWO YEAR TRANSITIONAL STATE PLAN FOR FEDERAL YEARS 1990-1991**, and its approved annual update and amendments. ADD Federal funds are made available each year to promote policy development, capacity building, and consumer empowerment and to demonstrate innovative approaches for the provision of services to benefit persons with developmental disabilities in Virginia. This is the source of funding for Developmental Disabilities Grants administered by the Developmental Disabilities Office of the Department of Mental Health, Mental Retardation and Substance Abuse Services. Priority areas and specific funding targets for Developmental Disabilities Grants are determined by the Board for Rights of the Disabled.

The Basic State Grant Program works in close cooperation with the two other components of the federal Developmental Disabilities Program in Virginia. The **Developmental Disabilities Protection and Advocacy System** is operated by the **Department for Rights of the Disabled**. It provides individual advocacy services for persons with developmental disabilities, including administrative dispute resolution and legal remedies for alleged violation of legal and human rights. Systems advocacy is provided through information and referral services, consumer mobilization assistance, and public awareness activities. The **Virginia Institute for Developmental Disabilities** is a **University Affiliated Program (UAP)** operated by **Virginia Commonwealth University**. It is an interdepartmental/interdisciplinary effort to provide preservice and inservice training and model services development to benefit persons with developmental disabilities. It also conducts policy/program research and information dissemination which contributes to state-of-the-art policies and practices to enhance the lives of persons with developmental disabilities and their families.

The Federal Definition Of "Developmental Disability"

Public Law 100-146, "The Developmental Disabilities Assistance and Bill of Rights Act Amendments of 1987", defines a developmental disability in Section 102(5) as:

"a severe, chronic disability of a person which -

- (a) is attributable to a mental or physical impairment or combination of mental and physical impairments;
- (b) is manifested before the person attains age twenty-two;
- (c) is likely to continue indefinitely;
- (d) results in substantial functional limitations in three or more of the following areas of major life activity;
 - self care
 - receptive and expressive language
 - learning
 - mobility
 - self-direction
 - capacity for independent living, and
 - economic self-sufficiency; and
- (e) reflects the person's need for a combination and sequence of special interdisciplinary, or generic care, treatment, or other services which are of lifelong or extended duration and are individually planned and coordinated."

Public Law 100-146 further states in Section 101(a) that:

- "(1) there are more than two million persons with developmental disabilities in the United States;
- "(2) persons whose disabilities occur during their developmental period frequently have severe disabilities which are likely to continue indefinitely;
- "(3) notwithstanding their severe disabilities, these persons have capabilities, competencies, and personal needs and preferences;
- "(4) family and members of the community can play a central role in enhancing the lives of persons with developmental disabilities, especially when the family is provided with necessary support services;
- "(5) persons with developmental disabilities and their families often require specialized lifelong assistance to be provided in a coordinated manner by many agencies and others in order to eliminate barriers for such persons and to meet the needs of such persons;
- "(6) generic service agencies and agencies providing specialized services to persons with disabilities sometimes overlook, inappropriately address the needs of, or exclude persons with developmental disabilities in their planning and delivery of services;
- "(7) public and private employers tend to be unaware of the capability of persons with developmental disabilities to be engaged in competitive work in integrated settings; and
- "(8) it is in the national interest to offer persons with developmental disabilities the opportunity, to the maximum extent feasible, to make decisions for themselves and to live in typical homes and communities where they can exercise their full rights and responsibilities as citizens."

The following conditions are **most likely** to result in individuals who are developmentally disabled, depending upon age of onset, severity of impairment(s), and multiple functional limitations:

- | | |
|--|--|
| - Autism | - Hereditary Progressive |
| - Mental Retardation
(Moderate/Severe/Profound) | - Muscular Dystrophies |
| - Cerebral Palsy | - Childhood or Adolescent
Psychosis/Schizophrenia |
| - Deaf-Blindness | - Huntington's Disease |
| - Spina Bifida | - Bronchopulmonary Dysplasia |

The following conditions **may** result in individuals who are developmentally disabled, depending upon age of onset, severity of impairment(s), and multiple functional limitations:

- | | |
|--|---------------------------------|
| - Early Onset Bilateral Deafness | - Tuberous Sclerosis |
| - Early Onset Bilateral Blindness | - Arthrogryposis |
| - Sickle Cell Anemia | - Hemophilia |
| - Systemic Lupus Erythematosus | - Cystic Fibrosis |
| - Cerebral Vascular Accident | - Limb Deficiency |
| - Juvenile Diabetes Mellitus | - Juvenile Rheumatoid Arthritis |
| - Spinal Cord Injury | - Multiple Sclerosis |
| - Traumatic Brain Injury | - Osteogenesis Imperfecta |
| - Post-Polio Paralysis | - Dwarfism |
| - Severe Craniofacial
Disfigurement | - Spinal Muscular Atrophy |

The following conditions are **least likely** to result in individuals who are developmentally disabled, depending upon age of onset, severity of impairment(s), and multiple functional limitations:

- | | |
|--------------------------------|------------------------------|
| - Epilepsy | - Immunodeficiency Disorders |
| - Specific Learning Disability | - Tourette Syndrome |
| - Heart Disease | - Asthma |
| - Curvature of the Spine | |

At the present time, the number of persons in Virginia (or any other state) with developmental disabilities cannot be precisely determined. This is largely due to the fact that the Federal definition of "developmental disability" is not currently used by any state agency in Virginia for either planning and policy development or for determination of eligibility for programs and services. Since its inception, the concept of developmental disabilities reflected in Federal legislation has evolved from a categorical approach to a functional approach. However, the Federal definition of "developmental disability" remains controversial because of its complexity and ambiguity.

The noncategorical (functional) definition of developmental disabilities designates criteria of early onset, severity of impairment(s), multiple functional limitations, chronicity, and need for a variety of individualized, coordinated services that are long-term or lifelong. All of these criteria can be difficult to consistently interpret or to operationalize. The intent of the federal Developmental Disabilities Act is to focus attention for comprehensive planning and policy development, particularly to benefit unserved and underserved constituencies. It does not intend to define eligibility and/or entitlement to specific programs or services.

Because Virginia has not conducted either a formal census or a valid prevalence study of the population of persons with developmental disabilities, the size of this population must be estimated. This can be accomplished with extrapolation using nationally established prevalence rates for developmental disabilities. The most commonly referenced prevalence rate promulgated by the Administration on Developmental Disabilities is 1.65% (Boggs & Henny, 1979). The Department of Planning and Budget (October 1986) has projected the total population of Virginia in 1990 will be approximately 6,096,700 individuals. Applying the 1.65% national prevalence rate results is an **estimate of 100,596 Virginians with developmental disabilities in 1990.**

Services available in Virginia to persons with developmental disabilities are not provided by the federal Developmental Disabilities Basic State Grant Program. It must be understood that currently no single State or local agency is responsible for serving persons with developmental disabilities. Local education authorities are responsible to provide or obtain appropriate special education and related services needed by eligible children with developmental disabilities. Persons whose primary impairment is moderate or severe mental retardation and/or mental illness or who have a substance abuse problem are under the auspices of the Department of Mental Health, Mental Retardation and Substance Abuse Services, and local Community Services Boards. Persons with developmental disabilities who are primarily physically handicapped or who have sensory impairments may receive various special services through such agencies (and their local units) as the Department of Rehabilitative Services, the Department for the Visually Handicapped, and the Department for the Deaf and Hard of Hearing. Persons with developmental disabilities also may be eligible to receive generic services available from such agencies as the Department of Health, the Department of Medical Assistance Services, the Department of Social Services, and the Virginia Employment Commission. At the local level, persons with developmental disabilities must seek assistance from a number of public and private agencies.

In particular, there are several Federally-assisted state programs which offer, or potentially offer, services to Virginia's population with developmental disabilities. These public programs are the most significant resources for persons with developmental disabilities, although not designated specifically for this population. With few exceptions, specific data related to extent or level of services provided to the developmentally disabled are unavailable. The Federally-assisted programs are organized in various ways to deliver their services, based upon their statutory and administrative requirements. As such, they are not presently organized into a comprehensive, coordinated service delivery system. Separate eligibility criteria and service networks have been established. These programs may support local or regional activities which may operate as subunits of State agencies, as agencies of local government, or by contractual arrangements with independent agencies. (See **Section II** and **APPENDIX A**)

B. PROCESS

In April 1988, the Planning Committee of the Board for Rights of the Disabled adopted and began implementation of a Work Plan to guide the preparation of Virginia's **1990 REPORT**. Members and staff representing the Board for Rights of the Disabled participated in a series of technical assistance activities conducted by the federal Administration on Developmental Disabilities (ADD) and the National Association of Developmental Disabilities Councils (NADDC). All members of the Board for Rights of the Disabled and its Committees were directly involved in the development and approval of the **1990 REPORT**. Overall coordination of the effort was provided by the Developmental Disabilities Office in the Department of Mental Health, Mental Retardation and Substance Abuse Services.

Manpower and resources for completing two components of the **1990 REPORT** were negotiated into solicited DD Grant projects supported from the Federal Year 1988 and 1989 Basic State Grant funds received by Virginia from the Administration on Developmental Disabilities. The Community Services Assistance Center (CSAC), a unit of the Virginia Institute for Developmental Disabilities (V.I.D.D.) at Virginia Commonwealth University (VCU), was responsible for the data collection and analyses concerning Federally-assisted and State funded programs in Virginia which are most relevant for persons with developmental disabilities (See **Appendix A**). V.I.D.D. is Virginia's University Affiliated Program, which has provided a variety of technical assistance to the Board for Rights of the Disabled. The Virginia Consumer Satisfaction Survey was conducted and its findings interpreted through the Consumer Empowerment Project (CEP) at the VCU Department of Rehabilitation Counseling. All surveyors were consumers with developmental disabilities or family members of consumers (See **Appendix B**).

Between the months of February and May 1989, four **1990 REPORT WORK SESSIONS** were conducted by the Planning Committee of the Board for Rights of the Disabled to examine specifically the areas of education, employment, community living, and unserved/underserved constituencies with developmental disabilities. Participants included members of the Board for Rights of the Disabled and its Committees, consumers with developmental disabilities and family members, representatives of advocacy organizations, public and private service providers, and State agency officials. Relevant information from previous conferences, studies, projects, and other appropriate documents were reviewed. Critical issues and preliminary recommendations were identified for each area.

In August 1989, the Board for Rights of the Disabled disseminated widely throughout the state draft **1990 REPORT** materials and recommendations. A written public comment period was conducted between August 15 - September 22, 1989. Public hearing sessions were held on September 18 and 19, 1989 (telephone call-in) and on September 20 and 22, 1989 (public meetings). Subsequently, the BRD Planning Committee prepared a final draft document. Finally, the Board for Rights of the Disabled held a specially called meeting on November 31, 1989 for final discussion and approval of the **1990 REPORT**.

SECTION II

SUMMARY OF FINDINGS FROM THE ANALYSIS OF FEDERALLY-ASSISTED AND STATE FUNDED PROGRAMS SERVING INDIVIDUALS WITH DEVELOPMENTAL DISABILITIES IN VIRGINIA

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To assess the success of Virginia's efforts to promote the independence, productivity, and integration of its citizens with developmental disabilities and to identify groups of individuals currently unserved or underserved, the Planning Committee of the Board for Rights of the Disabled directed the Community Services Assistance Center at Virginia Commonwealth University complete a comprehensive analysis of Federally-assisted and State funded programs operated by eleven State agencies. Analyses were completed by contacting and interviewing representatives from the administering agencies, reviewing current State plans, departmental reports, and other supporting documentation, and by consulting national data sets when available to compare Virginia's implementation of a specific program with current national trends.

All analyses were completed according to a prescribed format. After an overview which focused on the mission of the program, an **Eligibility** section summarized basic eligibility criteria for the program and highlighted areas in which Virginia's eligibility criteria differed from those of the Federal program. Second, a **Scope of Services** section outlined the major goals of the program, listed the types of services provided, and noted unique features of the program's implementation in Virginia. Third, an **Extent of Services** section provided basic data on the number of individuals served, number of individuals awaiting services, and the amount and sources of funds used to support the activities of the program. Finally, an **Effectiveness of Services** section reviewed evaluation studies that have been conducted on a program, discussed acknowledged program shortcomings, and outlined future plans to expand or modify programs. A compendium containing profiles of each of the 55 programs has been prepared as an appendix document for dissemination with the **1990 REPORT**. Key findings that synthesize the results of the analysis are described below.

1. Large groups of people with developmental disabilities have no access to services.

Significant gaps remain in Virginia's network of services for individuals with developmental disabilities that make it impossible for many people to access services they urgently need to promote their independence, productivity, and integration. With very few exceptions, Virginia generally follows Federal eligibility criteria for admission to almost all of the programs analyzed. Of major significance, however, is the fact that Virginia differs from the federal government and numerous other states in its application of the federal definition of developmental disability. No major service program in Virginia has adopted or attempted to incorporate the Federal definition of developmental disabilities into its basic eligibility criteria.

The lack of reliance upon the Federal definition of developmental disabilities has far-reaching ramifications for service delivery in the Commonwealth. Individuals with cerebral palsy, epilepsy, traumatic brain injuries, autism, orthopedic impairments, severe learning disabilities, and many other disabilities are unable to access much needed case management, housing and residential support services, personal assistance, family support services, and other services because no State agency has a legislative mandate to provide these services. As a result, persons with developmental disabilities who are not mentally retarded or mentally ill comprise the largest group of unserved and underserved individuals in the state.

A number of existing state programs also are presently underutilized by individuals with developmental disabilities. Varying eligibility definitions make it impossible to determine the precise number of individuals with developmental disabilities receiving services through the 56 programs. However, it is clear that persons with developmental disabilities are underrepresented in programs such as the Job Training Partnership Act, Centers for Independent Living, and Vocational Education. Social Security provisions designed to remove disincentives to employment, including Section 1619 (a) & (b) and Plan for Achieving Self-Support, are only minimally utilized as are Medicaid options such as the Ventilator Dependent Services, Personal Care Services, and Optional Services programs.

2. **Not all individuals with developmental disabilities in Virginia have equal access to needed services. Availability of critical services varies widely from community to community.**

Even where State agencies have a mandate to provide particular services to individuals with developmental disabilities, not all individuals who wish to access these services can find them readily available. Family support services, personal assistance services, accessible transportation, and case management services are all in critically short supply. Many important specialized programs, where they exist, are underfunded, lack trained personnel, and are not supported by the service system at large. Examples of constituencies who are significantly unserved or underserved are persons with autism, persons with traumatic brain injury, and persons with physical disabilities.

Particularly acute is the need by all constituencies with developmental disabilities for housing and associated residential support services. In spite of significant initiatives by the General Assembly, the Virginia Housing and Development Authority, and DMHMRSAS, waiting lists for community-based residential services extend many years in most communities.

In many instances, rural areas of Virginia face particularly acute shortages. Lack of accessible transportation services in many areas makes even obtaining necessary medical care a formidable challenge for many persons with developmental disabilities. Many programs, such as the Centers for Independent Living, are not available to individuals in many parts of the state. The capacity of many local programs is in large part dependent on the amount of local government funding which can be accessed to supplement Federal and State funds, which in and of themselves are greatly insufficient to address the present need.

This latter problem has become more serious in the last several years as Federal funds have significantly decreased as a percentage of agency budgets. For example, significant decreases in Federal contributions have forced agencies such as the Department of Social Services to reduce or eliminate programs once targeted toward individuals with developmental disabilities. In other State agencies (e.g. DRS, DMHMRSAS) level Federal funding has compelled the General Assembly to fund a significantly larger share of agency budgets with state appropriations.

3. Virginia has not moved rapidly enough to implement the concept of least restrictive environment as a guiding principle of its service delivery system and relies much too heavily on program alternatives that are neither appropriate nor cost-effective.

The mission statements of most State agencies reflect the concept of least restrictive environment as a way to enhance the independence, productivity, and integration of individuals with developmental disabilities. However, the General Assembly, major State agencies, and many local programs continue to dedicate massive resources to service alternatives that are often overly restrictive and segregated.

Less costly, proven service alternatives such as family support programs, personal assistance services, educational programs based in regular schools, and supported employment remain grossly underfunded. Large, facility-based programs persist as key components of the Commonwealth's residential (ICF-MR), educational (special centers for severely handicapped children) and vocational (sheltered workshop) service delivery network.

There are also inconsistencies among the initiatives undertaken by major state agencies. For instance, currently DMHMRSAS is proposing to close admission of children to state operated residential facilities while the Department of Education is considering significant expansion of a residential educational facility for children with various severe or multiple handicaps.

4. Virginia makes few efforts to systematically evaluate the effectiveness and efficiency of services and supports provided to individuals with developmental disabilities. Despite efforts of the Board for Rights of the Disabled, opportunities for consumers and families to express satisfaction and concern with the services they receive are rarely provided.

The lack of systematic efforts to evaluate the quality of services provided to consumers is a universal problem across all State agencies. This failure makes it impossible for the Board for Rights of the Disabled and the State agencies to effectively develop long-range plans to address the current and future needs of individuals with developmental disabilities. It also frustrates the General Assembly, which is unable to accurately determine the benefits individuals with developmental disabilities receive as a result of the enormous commitment of State fiscal resources. Problems with interagency cooperation and collaboration seriously diminish the economic and programmatic efficiency of services.

Particularly striking is the lack of consumer input into the program planning and evaluation efforts of many State agencies. Very few efforts are made to learn the opinions and concerns of individuals with developmental disabilities and their families. In a few agencies, this problem has grown to the point that an adversarial relationship has developed between the agencies and the constituencies they were created to serve.

SECTION III

SUMMARY OF FINDINGS FROM THE VIRGINIA CONSUMER SATISFACTION SURVEY

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SUMMARY OF FINDINGS FROM THE VIRGINIA CONSUMER SATISFACTION SURVEY

The Consumer Empowerment Project, located in Virginia Commonwealth University's Department of Rehabilitation Counseling, conducted the Consumer Satisfaction Survey under the direction of the Planning Committee of the Board for Rights of the Disabled to determine (1) the satisfaction with and needs for services, and (2) the current status of efforts to increase independence, community integration, and productivity among Virginians with developmental disabilities. VCU's Community Services Assistance Center also provided assistance related to data analysis. Surveyors and consumers to be interviewed were recommended by members of the Planning Committee and Board for Rights of the Disabled and by leaders of advocacy and consumer groups throughout the Commonwealth. Over 50 surveyors interviewed 309 Virginians with a wide range of developmental disabilities grouped into four major categories: cognitive (e.g. mental retardation), physical (e.g. cerebral palsy), sensory (e.g. visual impairment), and mental illness (e.g. schizophrenia). A survey instrument developed by Temple University and the National Association of Developmental Disabilities Councils was used to collect data. **All surveyors were either consumers or family members of consumers.**

Information was collected strictly from the point of view of the consumers and included: a) the consumer's experience with a variety of programs and agencies; b) the satisfaction of the consumer with his or her program experiences; c) the consumer's level of satisfaction with services currently being received; d) the consumer's reasons for dissatisfaction with services; e) information identifying the service providers; f) the consumer's current needs for additional services; and g) the consumer's reasons why needed services were not being received. Also, the consumers were asked about satisfaction with their lives, including school, jobs and where they lived. Finally, consumers shared information about how independent, productive and integrated into their community they were, and how important this was to them.

This summary is divided into two sections. The first focuses on priorities for expansion and improvement of services. The second section highlights the qualitative aspects of consumer lives and attempts to answer two questions: "What needs to be done to improve the quality of consumer's lives?" and "What are Virginia's current barriers to the full realization of independence, community integration, and productivity in the lives of Virginians with developmental disabilities?"

TARGETS FOR IMPROVED SERVICES

1. **Consumers with developmental disabilities are dissatisfied with sitting on the sidelines of life. They want the services and supports that will allow them to be active and integrated members of their communities.**

Consumers give high satisfaction ratings to all services aimed at increasing their community participation. Concurrently, they indicate a high level of need for services and supports such as community living assistance or training, self-help or support groups, and community support services. This finding is not surprising since the data indicate limited social community integration among members of the sample despite the fact that over 80% of adults rated community integration as important to their lives.

2. **Services and supports related to financial welfare dominate perceptions of satisfaction and need.**

The most consistent perceptions of satisfaction and need were related to financial welfare. Thus, high levels of need were indicated for income assistance, food assistance, financial management assistance, private health insurance, payment for medication, and payment or provision of medical equipment. Why is this area of assistance of such importance? Because having adequate income allows independence, community integration and productivity, values strongly endorsed by consumers. And because the ideal is so discrepant from reality - adult respondents to the survey had an estimated average annual project earned income of \$5,600.

3. **While satisfaction with Virginia's direct services is generally high, satisfaction with supports (that are often needed to use services effectively) is much lower.**

Assistance to Virginia's consumers comes in two forms. Services (e.g. sheltered employment) are provided to mitigate the effects of a consumer's disability. In contrast, supports (e.g. on-site attendant) are provided to increase the effectiveness of the service and/or to contribute to the quality of life of the consumer. A decade ago, Virginia's service system offered virtually all persons in a category of disability the same service mix regardless of a consumer's uniqueness. Today, there is a gradual trend toward designing a unique set of services and supports around the specific needs of a consumer. While this trend is commendable, there remains a consistent discrepancy between satisfaction with services and supports. For example, 72% of consumers receiving income assistance (i.e. SSI) are satisfied with that assistance, while only 55% are satisfied with the support that helps them make the most out of their income (i.e. financial management assistance). Educationally, satisfaction with regular school classes and career and professional education was 75% and 77%, respectively. In contrast, satisfaction with attendants and after-school tutors was 55% and 50%, respectively. Similar relationships held for services and supports for transportation and work. This pattern suggests a need for increased emphasis on improving supports in the service of major life roles and activities.

4. **Virginia's service delivery system often fails to target its resources with appropriate differentiation across disability groups.**

Results from our survey suggest that the satisfaction with and needs for services are often different for different disability groups. For example, there is a high need for transportation training for persons with physical disabilities, but not for other groups. Psychosocial rehabilitation is needed by persons with disabilities related to cognition and mental illness, but not other groups. On-site attendants are needed at work by many persons with physical and cognitive disabilities, but by few with sensory disabilities or mental illness. Fortunately, Virginia's service system is set up to provide different services for different disabilities. Unfortunately, it often fails to provide the services that are needed. When asked why they were not receiving needed services, a common response by consumers was "not eligible by type or degree of disability."

TARGETS FOR IMPROVING QUALITY OF LIFE

5. **The unavailability of work is a major barrier to increasing productivity and quality of life for many persons with developmental disabilities.**

Less than a third of adults in the sample worked full time, earning an annual projected income of just over \$12,000 (compared to a state average of \$16,516 in 1987). An additional 12% worked part time. Yet only 25% of our sample rated themselves as unable to work or retired. That means that 31%, almost a third, are available to work but are not working. Is working important? Eight of every ten consumers rated productivity as important to them as a life value. Yet almost a third of the adult consumers felt generally unproductive. The practical implications of these statistics are stunning. Only 23% of adult consumers own their own home (compared to about 65% of households in Virginia in 1980). Over half of the adult respondents remain living with a parent or in an institution. Though a large percentage indicated a need for additional education or vocational training, a dominant theme was that these are too expensive to obtain.

6. **The social support networks of most consumers are extremely limited.**

Current psychological literature strongly suggests that social networks positively contribute to mental health and life satisfaction. They may also contribute to physical health. Yet involvement in social networks by most persons with developmental disabilities is quite limited. The neighborhood social contacts of both children and adults with developmental disabilities appear constricted when compared to those of peers without disabilities. Many life roles, which serve to establish social networks (e.g. parent; worker; student) are either less available or more isolated from the mainstream for consumers. Only 23% of adults are members of consumer or advocacy groups despite a high satisfaction rating from persons who are members and a high level of stated need by consumers who are not members.

7. **Virginia's commitment to the independence of persons with developmental disabilities is often limited by the vested interests of primary caregivers and service delivery systems.**

Consumers show a very high level of independence in certain life activities (e.g., decorating one's room) but considerably less independence in other activities (e.g., handling personal finances). Lower levels of independence are often associated with the potential for inconvenience or liability on the part of caretakers or the service system. For example, only 24.1% of consumers whose primary caregiver was a service provider and 65.5% of consumers whose primary caregiver was a relative reported choosing their own job. Yet almost nine of ten (89.2%) consumers who indicated "self" as primary caregiver reported choosing their jobs. Assistance to increase level of independence in such activities as choosing one's own attendant or service provider and handling personal finances is limited and sporadic for many.

8. **While children and their parents are generally satisfied with their current service and family environments, this satisfaction often cloaks dependence, a potential barrier of importance to future life satisfaction.**

Although the majority of children and adolescents expressed satisfaction with their lives, they are often presented with barriers to future independence. Most live in loving and warm family settings and spend a great amount of their time in school. They are often given special assistance. For example, with 70% of youth in school, only 21% are in classrooms not providing special assistance. That we provide this for our children should comfort us. However, by providing a protected environment, a sense of independence may be inhibited. Relatively few youth are members of consumer groups though over half of their parents have joined at least one group. On a majority of indices of independence, caregivers providing foster care allowed more freedom of choice to consumers than did either parents or institutional staff. These examples suggest a discrepancy between life values and reality. While eight of every ten consumers endorsed independence as an important life value, over half of these same consumers characterized themselves as dependent.

9. **Many consumers remain isolated and limited in their involvement in "real world" roles and environments.**

While children seem to be fairly satisfied with their lives, adults appear somewhat less so. How does such a change come about? Our results suggest that an answer may be found in considerations of life involvement. Children's lives revolved around the roles of child, student, and leisure person. In contrast, adults are traditionally engaged in additional roles. Many roles taken for granted by persons with disabilities are simply not available to persons with developmental disabilities. Seventy-nine percent of our sample of consumers had never married and, or those who had married, 40% had divorced (spouse role). Only 32% of adult consumers worked full time (worker role). Only 42% of adults consumers living in multi-family homes or institutions were allowed to choose their leisure activities on weekends and evenings (leisure role). The likelihood of having children if you have a developmental disability remains so remote that no questions about the needs of consumer-parents were included in the survey (parent role). Yet pleas for participation in the "real world" abounded on our survey. This issue is important. Over 80% of adult respondents indicated that integration into community was important to their lives.

PREPARING FOR ACTION

This Summary has attempted to describe the "forest, but not the trees." It is believed that the image developed holds great promise for adding to the quality of life of Virginians with developmental disabilities.

As in any summary, the target image is broad in scope but lacks detail. That detail, the information to help in developing specific strategies for future work, is available in the body of the report. The reader of this summary is encouraged to gain a better understanding of the substance of these target issues by reading **"LIFE PATTERNS: A REPORT ON LIFE AND SERVICE SATISFACTION OF VIRGINIANS WITH DEVELOPMENTAL DISABILITIES,"** which will be disseminated as **APPENDIX B** of the **1990 REPORT**.

It is important to realize that dealing with the issues identified by this report is not only essential to enhance the quality of life for Virginians. Success is also realistic and attainable. It is time for Virginians to join together and continue.

SECTION IV

**EDUCATION
SUMMARY OF CRITICAL ISSUES AND RECOMMENDATIONS**

EDUCATION

Our Future Vision

Brad is a twelve year old Virginian who has spina bifida and a learning disability. Each morning, he rides to school on a lift-equipped bus. He is mainstreamed with age-appropriate peers in four of his six classes. Each of his teachers has received inservice training which enable them to help Brad compensate for his learning disability. They also understand spina bifida and how it affects Brad's functioning. All of the regular school personnel who come into contact with Brad have received inservice training on special education and disability issues. Brad's special education teachers are all certified in the areas in which they teach. The technological supports that Brad needs are readily available. The other children accept Brad, understand his disabilities, and respect his extraordinary ability to play the piano. Last year he played a song at the PTA Spring performance.

Once each year Brad, his parents, his teachers, and another representative from the school all meet together to formulate his Individual Education Plan. This group decided to meet in January and June to evaluate Brad's progress. The IEP contains goals and objectives which address not only his academic and vocational needs, but also mobility, self-esteem, social and leisure skills.

Virginia's Reality

Each day the bus ride to school is an hour long ordeal for Brad, who often arrives late. When Brad gets to his center-based school, he goes directly to the classroom which is in a separate wing of the school that is only occasionally used by students who are not in special education classes. The only contact he has with non-disabled students is when he sees them at assemblies or in the cafeteria. Brad cannot participate in the after school programs because none of the recreation workers are trained to work with children who have physical disabilities.

There are ten children with many different types of disabilities in Brad's class, yet the teacher does not have an aide. His teacher is certified in mental retardation, and is working towards a certification in learning disabilities. The only knowledge that she has about Brad's spina bifida has come from his parents.

Brad is still using last year's IEP. Although it was a struggle to develop it and appeared to be a battle won, his parents do not see the required services being provided. Brad's parents feel that he needs physical therapy three times a week, but the Local Education Authority can provide these services only once a week.

SECTION IV

EDUCATION SUMMARY OF CRITICAL ISSUES AND RECOMMENDATIONS

A special WORK SESSION was convened by the Board for Rights of the Disabled on February 23, 1989 to identify and discuss the most critical issues currently confronting the delivery of special education and related services in Virginia which are needed by and most appropriate for children and youth with developmental disabilities. Information and data from many sources were considered to identify barriers which prevent access to needed services and opportunities which would promote the independence, productivity, and community integration of young Virginians with developmental disabilities. Several cross-cutting issues were identified.

ISSUE #1 Lack of Consensus Regarding Federal and State Standards for Special Education and Insufficient/Inadequate Mechanisms for Monitoring Compliance

The issue of special education monitoring, both at the local and state level, was recently underscored by a report to the Governor from the Virginia Board of Education. Within that report it was noted that state and local monitoring has been inadequate, and, that the state had been very lenient in granting waivers to localities pertaining to class size, student placements, and teacher certification requirements. While relatively few violations of federal or state educational code can be found, there does exist a general perception that neither state or local agencies have vigorously embraced the spirit of equal and integrated education, as delineated by the Education for All Handicapped Children's Act (Public Law 94-142). Specific examples in which local and state monitoring mechanisms have been inadequate may be identified. These examples include: Least Restrictive Environment (LRE) placement, Individualized Education Plan (IEP) development and implementation, and adequacy of physical plants.

LRE There are inadequate provisions for LRE implementation due to the use of regional or local self-contained classes as the sole educational placement opportunity, particularly for students with developmental disabilities. In many localities there are no, or very limited, options. Few localities offer a full range of placement options from which families may select.

IEP Development Many parents are poorly informed about the IEP process, their rights and responsibilities within this process, or the availability of due process to contest IEPs. Parents are often asked to approve IEPs which have only been partially completed, without support services being specified. Parents are inadequately involved in the IEP development process. A report from the Board for the Rights of the Disabled indicated that nearly one-third of the respondents in a recent survey expressed dissatisfaction with the special educational services which they had received through the IEP. Additionally, 20% of the respondents felt that they had not received the services which had been recommended within their IEPs.

Physical Plant In many localities, the buildings and classrooms in which special education students received their instruction are in need of repair, are not accessible to students in wheelchairs, or, are too small to adequately accommodate the number of students and equipment that is required. Additionally, the simple location of special education classrooms within integrated schools is usually such that interaction and intermingling with nonhandicapped students is minimized. Examples of this that were cited included location in a separate wing of the building, at the end of a hallway, or in a trailer annex.

RECOMMENDATIONS

o The Department of Education should enforce implementation of "Standards of Quality" for the delivery of special education and related services by Local Education Authorities. Persons with developmental disabilities, parents and other family members, and disability advocacy organizations should have active participation through public comment opportunities and the legislative process in future revisions of these "Standards of Quality".

o The Department of Education should aggressively monitor and follow through with implementation of corrective action plans with Local Education Authorities to insure uniform compliance with the intent and requirements of P.L. 94-142.

o The Department of Education should provide technical assistance necessary to assure that educational standards and regulations are appropriately implemented. Particular areas needing attention are academic and functional curricula, assistive technology, vocational training, and leisure skills training. These areas should be directly reflected in Individual Education Plans for children and youth with developmental disabilities.

ISSUE #2 Insufficient Numbers of Appropriately Trained Educators, Administrators, and Related Services Personnel

Providing students who have developmental disabilities with a comprehensive and effective educational experience must begin with an adequate supply of properly trained and appropriately endorsed teachers who are experienced in their profession. Currently, students of special education are frequently provided with instructors who have not received adequate training, are not appropriately endorsed to provide instruction, or have limited classroom experience. A recent study by Dr. Frary at VPI provides some illustrative information on this issue. According to his results, 31% of all newly hired special education teachers in school year 1988 received teaching assignments in disability areas for which they were not properly endorsed. This figure has remained relatively constant during the past 5 years, as approximately 28% of all newly hired teachers are assigned to work with students experiencing disabilities for which the teachers have received very little training. Frary also evaluated the endorsement patterns all teachers (new and veteran) who were assigned to work with specific disability groups. As the data below indicates, there exist high rates of unendorsed teachers for a variety of different study disability groups. However, most notably, the issue of unendorsement seems to be the most prevalent among teachers of students with physical handicaps, severe/profound handicaps, and the preschool handicapped. It also should be noted that Virginia currently has no formal endorsement for teachers in the areas of autism, traumatic brain injury, and multi-handicapping conditions.

	FTE Teachers		
	Unendorsed	Total	% Unendorsed
1. Visually Impaired	6	31	19%
2. Physically Handicapped	33	52	63%
3. Hearing Impaired	11	140	8%
4. Severely Profoundly Handicapped	93	218	43%
5. Trainable Mentally Retarded	17	318	5%
6. Preschool Handicapped	119	409	29%
7. Emotionally Disturbed	115	658	17%
8. Educable Mentally Retarded	54	822	7%
9. Learning Disabled	346	2,914	12%
10. Speech/Language Disorders	21	771	3%

The issue of providing students with properly trained educational personnel however, extends beyond the relatively simple issue of endorsement. A host of other issues currently confront the effective delivery of appropriate special educational services. First, educational administrators, particularly at the local level, needs to be better informed and more knowledgeable about "state of the art" in special education. Quite often, many of the educational strategies and activities that are utilized within special education, are poorly understood and valued by local administrators, most of whom have had limited exposure to individuals with disabilities and special education. Second, regular and special education teachers need to have available technical assistance and consultative services to assist them in better understanding and educating their more challenging students. All too often, teachers in the classrooms, as well as their principals, or other local administrators, are faced with little or not support or guidance in addressing the needs of their students. The current SPH Technical Assistance Centers, operated by the Department of Education, are an excellent example of the types of supports that teachers and local school divisions require. Unfortunately, the availability of these supports are not universally available across the Commonwealth, nor are they universally available for the diverse population of disabilities that are experienced by students. Third, there is extensive need for noninstructional, support personnel within local schools. Professionals who are properly trained to provide related services such as medical support, occupational, physical, or speech therapy are in great demand, as are individuals properly trained in the areas of sign language and family support. Currently, many school divisions are unable to adequately staff these and related positions. Students often received inadequate educational support services which they need, or they receive no support services whatsoever.

Addressing the personnel issues confronting special education in Virginia must begin by first addressing the personnel issues of the educational system as a whole. There needs to be more sharing of joint training opportunities for both regular and special educators. Regular educators need to be better informed about special education; special educators need to better understand regular education. Additionally, strategies for enhancing the availability of trained teachers and the retention of veteran teachers must be explored. Finally, the development and training of school administrators needs to be evaluated in insure that all program administrators, from the principal level up, have an appropriate understanding of and appreciation for special education programming.

RECOMMENDATIONS

- o The Department of Education should increase its efforts to assure the employment of sufficient numbers of appropriately trained/certified special education teachers and related services personnel by local school divisions. Local school systems should employ additional personnel (e.g. psychologists, social workers, guidance counselors, physical therapists, speech pathologists, occupational therapists, audiologists, interpreters, etc.) and other providers of related services.

- o The Department of Education should establish, monitor, and enforce favorable caseload standards to assure that the needs of children and youth with developmental disabilities are met with appropriate special education and related services.

- o The Department of Education should strengthen its policies and procedures for the certification/re-certification of teachers, administrators, and other educational personnel to address the appropriate preparation of both "special education and related services" personnel and "regular education" personnel to work effectively with children and youth with developmental disabilities. Local Education Authorities should aggressively work to recruit and employ qualified personnel with disabilities.

- o The Department of Education should establish specific certification categories for teachers qualified to teach children and youth with **autism**, children and youth with **traumatic brain injury**, and children and youth who are **multihandicapped**. Teacher preparation programs in these areas must be established.

- o The Secretary of Education and the State Council on Higher Education should direct Virginia's institutions of higher education to expand and initiate new programs of appropriate education and preservice training for teachers and related personnel to become qualified/certified to provide special education and related services needed by children and youth with developmental disabilities.

ISSUE #3 Students with Developmental Disabilities are Exiting Schools (e.g., Aging-out) Without the Skills or Experience Necessary to Maximize their Current or Future Independence, Productivity, and Integration into Community Life

Students exiting special education all too often enter adulthood without the skills and abilities needed to lead an independent, productive, and socially integrated lifestyle. One recent report conducted by the VIDD Community Services Assistance Center surveyed teachers, social workers, and other caregivers of over 1,000 special education students, 18-21 years old, across the Commonwealth. The results of that study indicated that nearly 68% of the students would require day services in the future while 49% would require residential services. Additionally, a recent study conducted by Dr. Paul Wehman and his colleagues at Virginia Commonwealth University indicates that nearly 58% of individuals with mental retardation who graduated from special education programs in this state were unemployed. Similar figures may be identified for other developmental disabilities. Clearly, these results indicate that students exiting special education programs in this state are not adequately prepared to become productive members of society.

A number of factors may be identified to account for the post-school difficulties experienced by special education graduates. Most notably, there appears to be a lack of opportunities for students at the secondary school level to gain experience and training in occupational preparation. Very few school programs offer comprehensive vocational training and preparation that provides community-based instruction and job placement. Furthermore, many school divisions and local community service boards have not yet developed or implemented a coordinated, interagency approach to addressing the needs of graduating special education students. Clearly, the development of such transition plans and programs must be recognized as a critical aspect of the successful movement of students from school into adulthood. Additionally, schools need to develop and implement comprehensive and longitudinal vocational preparation programs which provide students with a variety of occupational experiences and allows students to receive instruction and training in regular employment settings, outside of the school. Similarly, students need functional instruction and experiences in areas of personal care and independent living to enhance their ability to live as adults in the community.

RECOMMENDATIONS

o The General Assembly should establish funding specifically to promote a comprehensive, coordinated system of services for children ages 0-2 years with developmental delay or those with a diagnosed condition or subject to environmental factors which have a high probability of resulting in delay. This should promote the collaborative efforts of community agencies, including school divisions, to comply with Public Law 99-457, Part H in the provision of early intervention and transition services for infants and toddlers.

o The General Assembly should require and provide funding for a formal statewide transition effort to promote collaborative activities between school divisions and community service agencies to provide for transition planning and delivery of transition services for youth with developmental disabilities who are exiting school and entering adult community life.

ISSUE #4 The Majority of Students with Developmental Disabilities are Regularly Denied Access to, and Experience with, Age-appropriate Peers Who Are Not Handicapped

For many students in special education, and for the majority of those identified as developmentally disabled, school is often an experience share only with other children who are themselves disabled. In 1987, approximately 15% of all children with developmental disabilities received their education outside of their home community, either in regional programs, in-state private programs, state operated training centers, or out-of-state placements. As such, a significant number of special education students do not regularly receive their education in their own community. Even more of these students do not receive their education at their home school, that is, the one in which their sisters and brothers and neighborhood nonhandicapped friends attend. One recent report indicated that 63% of all students with severe disabilities attended school in segregated settings, where they have no opportunity to interact with nonhandicapped peers. Additionally, placement within such segregated settings is often made with little regard for age-matching; that is, placing students with other students of comparable age. One recent report indicated that 75% of the SPH classrooms in Virginia had students that varied in ages of 4 - 9 years. That means that student who are 5 years old could be in the same classroom as students who are 13 or 14 years old.

RECOMMENDATION

o Department of Education should implement policies and regulations to insure that all children and youth with developmental disabilities are educated to the maximum extent possible and appropriate with non-disabled peers and within their home communities. A full range of appropriate placement options should be available.

SECTION V

**EMPLOYMENT
SUMMARY OF CRITICAL ISSUES
AND RECOMMENDATIONS**

EMPLOYMENT

Our Future Vision

Diane, a 25 year old young adult with mental retardation, graduated from the special education program at her local high school. The last four years of her education included an emphasis on the transition from school to the workplace. Diane was involved in three experiences within different types of industries and has decided that she has the most interest and skills related to botany.

Through the Commonwealth's Job Match program, Diane has spent the last three years working in a greenhouse. The greenhouse received tax credits during the first year of Diane's employment. Although her original responsibilities focused on plant cultivation, she was recently transferred to the sales division in customer service due to her vast knowledge of plants and her desire to share this information with others.

Diane receives vouchers from the State in order to purchase transportation services. Her job coach visited her on a monthly basis during the first year of her employment and still remains in contact with her on a regular basis.

Virginia's Reality

When Diane turned age 22 years, she was too old to continue with her special education program. The program had not prepared her with any sort of vocational education. She has "aged out" and now appears not entitled to receive services from anyone. Diane's parents put her on the State agency waiting list for employment services. She spent the next three years sitting at home, watching television and waiting.

After three years without any socialization and limited intellectual stimulation, Diane met with an employment counselor. During her time away from school, she had regressed in many areas. After nine more months on a waiting list, Diane was placed in a sheltered workshop, stuffing envelopes. Her hourly salary is below the Federal minimum wage, and she has quickly become bored with the simple, repetitive task. Although she now has an activity during the day, Diane's parents must provide her transportation because there are no public transportation services in the community.

Diane cannot afford, nor is she prepared, to live on her own.

SECTION V

EMPLOYMENT SUMMARY OF CRITICAL ISSUES AND RECOMMENDATIONS

A special WORK SESSION was convened by the Board for Rights of the Disabled on March 8, 1989 to identify and discuss the most critical issues in Virginia which currently affect the vocational status and employment opportunities of individuals with developmental disabilities. Information and data from many sources were considered to identify barriers which prevent access to needed training, services, and supports to enable persons with developmental disabilities to obtain and maintain employment. Several cross-cutting issues were identified.

ISSUE #1 Insufficient and Inadequate Services and Supports to Permit Remunerative Employment

Currently, service delivery systems in Virginia are fragmented and inadequate to support employment of persons with developmental disabilities. These inadequacies are most pronounced with regard to funding levels, long-term supports, optional ancillary resources, and opportunities to access rehabilitation technology.

Results from a variety of recent studies conducted within the Commonwealth clearly indicate that persons with developmental disabilities experience chronic and severe underemployment and unemployment. The Community Services Assistance Center (CSAC) located at Virginia Commonwealth University, has conducted a number of studies using the Developmentally Disabled Persons Community Needs Survey. Results of this Survey of 1,500 individuals have indicated:

- Forty percent of the survey respondents expressed a need for vocational training services
- One third of the respondents have no regular daytime activity
- Less than 10% of the respondents are working in full or part-time positions
- One third of the respondents are in a sheltered workshop or activity center where wages are typically very low

Comparable results were also obtained from the recent Board for Rights of the Disabled Survey of Virginians with Disabilities as well as follow-up studies of former special education students conducted by Dr. Paul Wehman and his colleagues at VCU.

The present system of providing employment services to persons with developmental disabilities was viewed by the participants of this WORK SESSION as grossly inadequate. Many rehabilitation facilities, sheltered workshops and other employment service agencies are experiencing lengthy waiting lists for admission to services. Currently, DMHMRSAS estimates that over 1,600 individuals with mental retardation have been identified who are on waiting lists to receive employment support services. Additionally, DMHMRSAS estimates that by 1994, just five years from now, well in excess of 15,000 individuals will require some form of day or employment support. These estimates should be considered conservatively since DMHMRSAS is concerned primarily with individuals considered mentally retarded.

In addition to addressing the absolute gap between service need and service availability, group members also identified insufficient funding of ongoing employment supports, inadequate resources particularly with regard to personnel and staff development, and limited availability of quality rehabilitation technology services as major issues limiting the full productive employment of persons with developmental disabilities.

RECOMMENDATIONS

- o The General Assembly should provide sufficient permanent funding to expand and maintain long-term supported employment opportunities for persons with severe physical, sensory, and/or mental disabilities. This should include funding to provide for appropriately trained personnel necessary for supported employment activities.
- o The General Assembly should provide incentive funding to encourage rehabilitation facilities with sheltered workshops to develop and expand community supported employment opportunities.
- o The General Assembly should mandate the implementation of a coordinated, interagency job-matching placement and follow-along system for persons with disabilities. This system should include the collaborative efforts and participation of all appropriate, publically-supported State and local agencies and programs.
- o The General Assembly should provide funding for a voucher system to provide needed ancillary support services (e.g. transportation; procurement of adaptive equipment, mobility aids, or communication devices; child care; etc) to allow employment and promote the independence of individuals with developmental disabilities.

ISSUE #2 Inadequate Efforts to Communicate the Ability and Availability of Persons with Developmental Disabilities to Engage in Meaningful and Productive Employment

A major barrier to the realization of full productive employment of persons with developmental disabilities is the lack of awareness and expectations among professionals, parents, employers, and persons with developmental disabilities themselves, regarding the employment capacity and availability of these individuals. Historically, persons with developmental disabilities have been perceived to possess minimal potential for employability. The past 10 years, however, has clearly and unequivocally refuted this notion and has demonstrated that, given appropriate services and supports, individuals with developmental disabilities can become productive and contributing members of the workforce.

The limited expectations of and by persons with developmental disabilities need to be confronted from a variety of fronts. Individuals with developmental disabilities need to be made aware, through effective education and rehabilitation, that they are capable of productive employment in integrated settings which provide them with meaningful wages. Efforts need to be undertaken in our public schools to insure that teachers are providing their students with the right message: that in spite of your disability you can and you should expect to become a member of the workforce. Teachers need to be better educated and

trained so that they are also providing their students with the right vocational preparation: training in community-based integrated employment settings on tasks that are performed by nonhandicapped persons for financial remuneration. Local Education Authorities should aggressively work to recruit and employ qualified personnel with disabilities. Such individuals would not only provide needed manpower, but would also serve as positive role models for students with and without disabilities.

Parents must also be educated of the employment abilities of their developmentally disabled offspring. Quite often, parents are incorrectly viewed as a major barrier to the employment of developmentally disabled individuals. We must begin to recognize and respond to the fact that parents' hesitancy regarding the employment of their children is often the direct result of the information that parents receive from professional service providers, including teachers, pediatricians, psychologists, rehabilitation counselors, case managers, and others. As such, efforts need to be taken to insure that all professionals concerned with persons experiencing developmental disabilities are well aware of the employment abilities of persons experiencing developmental disabilities.

Finally, and perhaps most importantly, both the public sector and the business community in Virginia needs to become better informed of the employment ability and availability of persons with developmental disabilities. Quite often, employers are viewed as a major barrier to the employment of persons with developmental disabilities. Recent experiences, particularly within supported employment, however, have consistently shown that informed and educated employers can often be a major asset to the employment of persons with developmental disabilities.

RECOMMENDATIONS

- o Local Education Authorities and community agencies should work collaboratively using "Virginia's Plan of Coordinated Transitional Services for Youth and Young Adults with Disabilities" to educate students with developmental disabilities, family members, employers, and the public concerning the employment potential of individuals with developmental disabilities.

- o The General Assembly should mandate the Secretary of Administration and the Department of Personnel and Training to strengthen Virginia's commitment to affirmative action in hiring and promoting persons with disabilities within all areas of State government through explicit directives, education, and monitoring.

- o The General Assembly should create State tax incentives which will benefit employers who hire and/or provide long-term supports which allow persons with developmental disabilities to maintain remunerative employment.

ISSUE #3 Empowerment of Consumers with Developmental Disabilities to Have Options and Make Choices Regarding Employment

In spite of the gains that the Commonwealth has made in recent years to expand the availability of employment services for persons with developmental disabilities, there still exists limited diversity in the options available to persons. As a result, most Virginians with developmental disabilities have very little choice in the employment services they receive. In many localities, only one or two forms of employment services may be available. As such, individuals must often make the choice of accepting a service which they may not desire or need, or accept no service at all. This predicament is not at all uncommon, particularly within the smaller and more rural regions of the Commonwealth. In order to address the individually determined employment needs of persons with developmental disabilities, an array of diverse employment options must be locally available.

The issue of providing individuals with choices and options, however, requires more than just expanded service options. The manner in which clients are regarded by their rehabilitation counselor, case manager, employment specialists, and other professional service providers needs to be carefully examined and re-evaluated. Persons with developmental disabilities need to be value as consumers of services, rather than clients. These consumers, like consumers of other goods and services should be afforded maximal control over the selection of specific services and service providers, as well as the nature of service delivery system.

RECOMMENDATIONS

- o The General Assembly should provide sufficient permanent funding to expand and maintain long-term supported employment opportunities for persons with severe physical, sensory, and/or mental disabilities. This should include funding to provide for appropriately trained personnel necessary for supported employment activities.

- o The General Assembly should provide incentive funding to encourage rehabilitation facilities and sheltered workshops to develop and expand community supported employment opportunities.

- o The General Assembly should provide funding for a voucher system to provide needed ancillary support services (e.g. transportation; procurement of adaptive equipment, mobility aids, or communication devices; child care; etc) to allow employment and promote the independence of individuals with developmental disabilities.

- o Local Education Authorities and community agencies should work collaboratively with the Department of Education using "Virginia's Plan of Coordinated Transitional Services for Youth and young Adults with Disabilities" to educate students with developmental disabilities, family members, employers, and the public concerning the employment potential of individuals with developmental disabilities.

SECTION VI

COMMUNITY LIVING
SUMMARY OF CRITICAL ISSUES AND RECOMMENDATIONS

COMMUNITY LIVING

Our Future Vision

Frank is an adult with cerebral palsy. His case manager allows Frank to make his own decisions and helps him to access the supports he needs to be integrated into his community. He lives in the community where he grew up, in an apartment complex where he has a live-in roommate/personal assistant. Frank's apartment and the apartment complex recreation center are accessible. He enjoys meeting and developing relationships with his neighbors at the weekly social activities at the recreation center.

Frank also chooses the services that he receives and where he receives them. He has access to many technological aids which help him to be independent. Before making a purchase, he can try these aids at the Center for Independent Living, and their costs are covered by Medicaid. Frank usually uses public transportation, yet when he wants to visit friends who do not live on the bus route, he can call the paratransit service. This service will accommodate his request up to an hour before he would like to be picked up.

Virginia's Reality

When Frank turned 22 years old and his aging parents did not feel that they could adequately care for him, he was placed in a Home for Adults. Although this home is in his city, it is not within his community and it is very difficult for his parents and friends to visit him. He had already spent ten years in this setting which is not appropriate for his intellectual ability. Yet, because of the severity of his cerebral palsy, Frank's case manager felt that an institution was his only alternative. Although, it had never been a problem in the past, Frank is now frequently depressed and, at times, the staff states that he is very uncooperative.

In the home, Frank depends on staff for virtually everything. He would like an electric wheelchair, but cannot afford it and, therefore is not independently mobile. When Frank asks staff about technological supports, they are unaware of what is available, but always says that it is too expensive anyway.

SECTION VI

COMUNITY LIVING SUMMARY OF CRITICAL ISSUES AND RECOMMENDATIONS

A special WORK SESSION was convened by the Board for Rights of the Disabled on March 21, 1989 to identify and discuss the most critical issues in Virginia which influence opportunities for community living and improved quality of life for individuals with developmental disabilities. Information and data from many sources were considered to identify barriers which prevent access to needed services or supports which would permit and enhance the maximum independence, productivity, and integration of Virginians with developmental disabilities. Four cross-cutting issues were identified.

ISSUE #1 Consumer Empowerment for Community Living

A significant concern currently confronting the issue of living in the community is the lack of a strong consumer-based orientation to the planning and delivery of services for persons with developmental disabilities. The traditional orientation is typified by the consistent use of the term 'client' to refer to individuals who receive services. Current funding mechanisms for the service delivery system provide the individual with few or no choices regarding service options, since funds are provided to agencies and programs rather than to the individuals themselves. Individuals with developmental disabilities must either agree to participate in the program or services offered, or to receive no services at all. The consumer is not empowered to seek alternative services or alternative providers. The essential problem is the lack of real choices for persons with developmental disabilities. Current funding mechanisms should be modified so that individuals, not the agencies and program, experience maximum prerogative and options in service selection and utilization. One such modification could entail the Commonwealth providing funds to individuals, possibly in the form of service vouchers, so that individual consumers could select the types of services/supports they wish to receive as well as the providers from whom they would obtain these services/supports.

The Commonwealth should assume an active role in empowering consumers with developmental disabilities and in promoting consumerism within the human services delivery service network. Virginia should promote, fund, and then leave alone organizations or associations which promote self-determination and consumerism on the part of persons with developmental disabilities. Additionally, there is a lack of participation by individuals with disabilities on governing boards of most state and community agencies that provide services/supports. Representation by individuals with disabilities on these boards was identified as a critical need for promoting consumerism within the disability field. Finally, quality assurance programs and methods of evaluating program effectiveness was identified as an area in which consumerism is needed. Specifically, there is need to assure program quality from the perspective of the consumer, not the provider or the funding agency. It was suggested that the Commonwealth assess the possibility of establishing consumer monitoring teams, made up of individuals with disabilities, to conduct program evaluations which reflect consumer views and values.

- o The Governor should promote and monitor self-advocacy and consumer empowerment in all public agencies by requiring through an Executive Order that there be continuous consumer participation in decisions concerning the planning and implementation of services for individuals with disabilities.

- o The General Assembly should establish and make uniformly available throughout the state a Quality Assurance System that is **independent from agencies which directly fund/provide services**, that actively involves consumers with developmental disabilities and their families, and which evaluates programs and services with criteria of individual outcomes relating to independence, productivity, and community integration.

- o The Department for Rights of the Disabled should collaborate with Centers for Independent Living and disability advocacy organizations to sensitize/educate health care personnel in appropriate interaction with persons with developmental disabilities and their families and in the use of existing information and referral services which will assist them.

ISSUE #2 Insufficient and Inadequate Community Services and Supports

During the past few years, the Commonwealth has begun to enhance the availability of housing for persons with disabilities. None the less, if one is elderly, a child, physically disabled, or experiencing multiple or severe disabilities, needed residential supports are very difficult, if not impossible to obtain. Extensive waiting lists continue in most localities of the Commonwealth. Several hundred individuals currently living in state operated training centers await community options, but are unable to locate available community residential placements. The Community Needs Survey identified significant numbers of individuals currently living at home with elderly parents. There are persons in community residences who should have less restrictive options than those they are currently using. There are families who lack alternatives, including family support or respite services, who are experiencing great stress. Clearly, the Commonwealth, in spite of recent efforts, is faced with a continuing serious challenge to provide the range of diverse supports which allow individuals with developmental disabilities to maximize their community living.

Two areas of direct support which were repeatedly identified by speakers as most critical were the areas of Personal Assistance Services and Family Support Services. Personal Assistance Services are desperately needed across the Commonwealth to address primarily the needs of Virginians with developmental disabilities who have physical impairments. Many of these individuals do not need ongoing training or supervision. They simply need someone to assist them with personal care or with household-related activities which they are physically unable to do without help. Many individuals are able to lead normal, productive lives with the use of intermittent services from a personal attendant who may provide assistance for only part of the day. Currently, personal assistance services are in extreme short supply and not funded. As a result, many individuals with physical disabilities are confined to convalescent centers, nursing homes, training centers, or other restrictive and costly residential service programs.

Development of a comprehensive system of Family Support Services is a very frequently identified need. Families of individuals with developmental disabilities (including single parent, adoptive, and foster care families) need to have access to a system of supports which will allow them to remain intact. These supports may include financial assistance, respite care, training and behavior management consultation, in-home adaptation and barrier-free modification, transportation, and adaptive equipment. The specific forms of family support provided should be determined by the family itself. The unavailability of these services has resulted in the out-of-home placement of many individuals whose families were willing for them to remain home, but were unable to provide them with the necessary level of support.

One of the most commonly cited forms of needed family support is that of respite care, or temporary supervision of their family members. Sometimes this respite is needed just so that the family can "get away" from the stresses and demands that may be associated with their family member. At other time, however, families may require emergency respite services in the event of a crisis. The length of respite needed may vary from a few hours to a few weeks and could be provided within a family home, a respite provider's home, or at a nearby community facility.

A final area of concern relating to residential alternatives and support services was the issue of accessibility. Speakers noted that accessibility of housing continues to be a serious issue. Accessibility in terms of physical access and adaptability for persons with mobility or sensory impairments represents one aspect of this issue. Additionally, monetary accessibility, in terms of reasonable prices within the resources of most persons with disabilities represents another aspect of this issue.

RECOMMENDATIONS

INCREASED SERVICES AND SUPPORTS

- o The General Assembly should require the Department of Medical Assistance Services to work collaboratively with appropriate State and local agencies to determine the feasibility of expanding the scope and increasing the individuals eligible to participate in all aspects of the Medicaid program, particularly to increase opportunities for community-based habilitation/rehabilitation services needed by persons with developmental disabilities.

- o The General Assembly should provide permanent funding to significantly expand and make uniformly available **supported employment** services, **independent living** services, and **rehabilitation engineering/assistive technology** services. The administration and implementation of these services should be coordinated among DRS, CILs, DMHMRSAS, CSBs, and other appropriate state and local agencies.

- o The General Assembly should require and provide funding to establish and make uniformly available a statewide Personal Assistance Services (PAS) system of consumer-directed, individualized supports necessary to promote the maximum independence and productivity of individuals with developmental disabilities. This system would provide attendant services to assist in accomplishing activities of daily living; it would include financial/technical assistance to obtain adaptive equipment, communication devices, and mobility aids which maximize individual funding.

- o The General Assembly should establish State tax credits/tax deductions for families or individuals who provide a home and supervision/care for family members or other persons with developmental disabilities, if such living arrangement and care represents the "least restrictive environment" available during the applicable tax year.

- o The General Assembly should require and provide funding to establish a multifaceted system of Family Support Services (FSS) to be uniformly available throughout the state for all persons with developmental disabilities. This flexible system would respond to changing individualized needs of families; it would include direct support services, stipends/vouchers to purchase or obtain services, and financial/technical resources to obtain adaptive equipment, communication devices, and mobility aids which maximize individual functioning.

- o The General Assembly should support the establishment and maintenance of local or regional Family Support Resource Centers throughout the state. These would provide centralized information about and referral to local and regional programs and services for persons with developmental disabilities, planning and problem-solving consultations, counseling and specialized training for family members and/or primary caregivers, and respite services.

HOUSING

- o The Board of Housing and Community Development should insure compliance with the federal Fair Housing Amendments Act of 1988 through the Uniform Statewide Building Code. Enforcement of the Act's adaptability and accessibility requirements should receive high priority from the Department of Housing and Community Development, and continuing education and training should be provided to building designers and inspectors.

- o The General Assembly should establish and fund a rental assistance program for persons with disabilities who meet low income criteria.

- o Agencies of State government providing housing and other services to persons with disabilities and disability advocacy organizations should work collaboratively with the housing industry to make residences and support services, including personal assistance, available to people with disabilities.

- o The Department of Housing and Community Development should expand financial and technical assistance for modifying existing housing units to increase accessible housing opportunities for persons with disabilities.

PERSONNEL PREPARATION

- o The Secretary of Education and the State Council on Higher Education should direct Virginia's institutions of higher education to expand and initiate new programs of interdisciplinary preservice training to prepare professionals and paraprofessionals to deal with the assessment, training, and other service delivery needs of persons with developmental disabilities.

- o The General Assembly should require and provide funding for a statewide system of personnel support which includes inservice training and programmatic technical assistance for professionals and paraprofessionals who participate in the public/private developmental disabilities service delivery network.

PREVENTION

- o The General Assembly should require and promote implementation of primary, secondary, and tertiary prevention strategies to minimize the occurrence of medical conditions or mental/physical impairments which may result in developmental disabilities.

ISSUE #3 Lack of Effective Case Management Services

A third issue identified by the group was the current state of comprehensive case management services. Currently, these services are viewed as inadequate to meet current demand, too rigid and inflexible to meet individualized needs, insensitive to individual choice, and ineffective given the current gap in service availability. The current gaps in residential and employment services and the general orientation toward providing programs rather than support services does not adequately allow case managers to individualize the supports of their consumers, resulting in the use of services that may not be suited to their needs. Additionally, the number of consumers serviced by a case manager needs to be carefully monitored. It is unrealistic to assume that a case manager can effectively support persons living in the community with a caseload of 50 - 100 persons.

Much of the issue of comprehensive case management is structural in nature. Currently, case management is provided by CSBs to assist individuals living in the community by making available to them various services or programs available. Concomitantly, the CSB is also providing the services or supports identified by the case manager. Such a situation obviously presents great potential for conflict of interest to occur as case managers must not only concern themselves with their client's needs, but those of the CSB, their employer, as well.

A system of comprehensive case management is needed that is independent of the service providers and flexible enough to meet the needs of individuals over time. However flexible this system is, it will remain ineffective so long as there are insufficient services available from which the case manager and consumer may select. Without an adequate array of services and supports, comprehensive case management becomes nothing more than a meaningless word and the job of case managers is reduced to that of paper shuffling and moving individuals from one bad situation to another.

Due to the critical role which case managers play, it is essential that the Commonwealth insure the adequate supply of well trained individuals. Case managers serve as the liaison between consumers and support systems, determine which individuals are in need of supports, identify the types of supports needed, facilitate and monitor the provision of these supports. Obviously, if individuals with developmental disabilities are to receive the types of supports needed to maximize their community living, it will be due, in part, to the activities and coordination of competent, well-trained case managers. As such, it is critical that the Commonwealth provide adequate incentives to insure a sufficient supply of well-trained case managers.

RECOMMENDATION

- o The General Assembly should establish and make uniformly available throughout the state a system of case management services for persons with developmental disabilities that is **independent from agencies which directly fund/provide services**. Case load sizes should be limited to 20-40 persons to allow individualized, consumer-directed services.

ISSUE #4 Lack of Accessible/Affordable Transportation

The lack of affordable, accessible, and reliable transportation represents one of the more critical barriers that currently limit the community living options of persons with developmental disabilities. While some individuals in urban areas may complain about the accessibility or reliability of their transportation system, most individuals in the more rural areas of the Commonwealth have no public transportation system available to them at all. The lack of appropriate transportation option poses a serious impediment to community living and cuts off many individuals from their community of friends and family. Many individuals with developmental disabilities who live at home with their family or by themselves cannot access jobs for which they are qualified because they have no way of getting to and from work. Creative transportation networks need to be developed.

RECOMMENDATIONS

- o The General Assembly should provide incentive funding for localities to promote purchase of lift-equipped buses and to encourage continuation and expansion of other transit services which promote mobility and independence for Virginians with disabilities. In addition, uniform equipment standards should be required by the Department of Transportation.

- o The General Assembly should require that formal transportation coordination agreements be developed and implemented among local providers of transportation services, especially in rural areas.

- o The Department of Transportation should provide funding to develop and implement an ongoing program of training for users who have disabilities and providers who serve persons with disabilities in public transportation systems.

- o The General Assembly should establish and fund a voucher program to allow individuals with developmental disabilities to obtain transportation services needed to work, to receive services, to perform daily activities, or to participate in community activities.

SECTION VII

UNSERVED/UNDERSERVED CONSTITUENCIES WITH DEVELOPMENTAL DISABILITIES SUMMARY OF CRITICAL ISSUES AND RECOMMENDATIONS

UNSERVED/UNDERSERVED CONSTITUENCIES WITH DEVELOPMENTAL DISABILITIES

Our Future Vision

At a very young age, Beth's pediatrician determined that she had autism. At the time of diagnosis, Beth's parents contacted, through a state agency, Case Managers Unlimited. This non-profit organization provided them with a case manager for Beth. This service, like any others required by Beth and her family, is funded by a state-wide voucher system.

Mary, Beth's case manager, began by supporting the family through education. She helped Beth's parents and older brother understand what autism meant and how it affected Beth. Mary also served as a liaison arranging services for Beth, including school, after school and summer recreation program, transportation, and financial assistance. All of the services and programs that Beth needed were found in her community. When Beth's parents wanted to go out for an evening, out of town for a weekend, or they just needed someone to be with Beth for a few hours, they felt very comfortable using the respite services available.

When Beth turned 22 years old, it was a time of celebration. She was able to move into a group home with three other young women. Highly trained staff help with tasks such as meal preparation and transportation to work. Beth's communication devices (i.e. her "day planner" which includes photographs detailing her schedule) facilitate her communication with persons not knowledgeable about autism. Mary, the residential staff, and Beth's job coach meet on a regular basis to ensure Beth the stability she needs to function best.

Virginia's Reality

After seeing many pediatricians and specialists, Beth was finally diagnosed as autistic. Doctors recommended that she be institutionalized immediately. Beth's parents wanted to keep their daughter at home. Her mother quit her job because they could not find anyone who was willing or knowledgeable enough to care for Beth.

Beth's parents tried to get services for her, but there did not seem to be an agency that was required to serve people with autism. There were no programs or services in the community for Beth. She started school in a special education class, but due to their lack of training, the teachers were soon unable to control her maladaptive behavior. After a long due process hearing, the school system did agree to pay for a residential placement for Beth.

After six years without any respite, not being able to take vacations or even go out to dinner, Beth's parents felt that they had no other option. Beth was sent to a residential school, five hours away from home.

Beth will soon be 22 years old and her parents are very concerned that she will not have a place to live. Although Beth had access to communication devices at her school, her parents cannot afford to purchase them. There are three-year waiting lists for most group homes throughout the state and her parents are not even certain that the staff in such homes are knowledgeable enough about autism to truly help Beth. She has limited vocational skills, but the staff at the sheltered workshops are not sufficiently trained in autism to provide her the supports she needs.

SECTION VII

UNSERVED/UNDERSERVED CONSTITUENCIES WITH DEVELOPMENTAL DISABILITIES SUMMARY OF CRITICAL ISSUES AND RECOMMENDATIONS

A special WORK SESSION was convened by the Board for Rights of the Disabled on May 24, 1989 to identify and discuss the most critical issues in Virginia pertaining to unserved/underserved constituencies of persons with developmental disabilities. Particular consideration was made to how the existing human services delivery system might be modified and/or expanded to remove barriers to services and to create new service opportunities for Virginians with developmental disabilities. The following overarching issues were identified.

ISSUE #1 Inequities Among Constituencies with Developmental Disabilities

Policy makers in Virginia have not adequately acknowledged and addressed the discrepancies and inequities that exist among the publically-supported opportunities made available to various populations with disabilities. This situation affects, but is certainly not limited to, individuals with developmental disabilities.

Virginia has made a commitment to provide emergency treatment services needed by persons with mental health, mental retardation, and substance abuse conditions, and to promote the development of a full-range of appropriate "Core Services" for them, including prevention and early intervention, case management, day support/vocational, and residential. However, Virginia has not made a comparable policy and resource commitment to provide "Core Services" for persons with developmental disabilities who have severe sensory and/or physical impairments.

Limited direct services and indirect assistance are available to persons with sensory impairments through the Department for the Visually Handicapped (DVH) and the Department for the Deaf and Hard of Hearing (DDHH). Many persons with developmental disabilities are also not able to obtain appropriate vocational habilitation/rehabilitation services, independent living rehabilitation services, or other needed assistance from the Department of Rehabilitative Services (DRS) or local Independent Living Centers (ILCs). This is because of both eligibility limitations and funding/manpower limitations. However, there is also a lack of coordinated and comprehensive planning being conducted for constituencies with sensory and/or physical disabilities.

The Board for Rights of the Disabled is aware of these gaps in services and will initiate a coordinated approach through the PLAN OF COOPERATION to identify and address the service needs of the unserved/underserved populations with developmental disabilities in Virginia.

RECOMMENDATIONS

- o The Secretary of Health and Human Resources and the Board for Rights of the Disabled should identify and address through the PLAN OF COOPERATION the service needs of constituencies with developmental disabilities who are currently unserved/underserved.

- o The General Assembly should authorize and provide funding for a legislative study to determine the agency/agencies responsible in Virginia to provide/coordinate comprehensive services for **all persons with developmental disabilities**, based upon the federal definition in the Developmental Disabilities Act.

ISSUE #2 Lack of Documentation Concerning Numbers and Service Needs of Persons with Developmental Disabilities

Virginians with developmental disabilities are a large, heterogenous population with multiple and chronic disabilities who are seriously unserved and underserved. The majority remain dependent and unemployed due to the lack of needed long-term services and supports which could improve their functioning and quality of life. Existing programs and services are fragmented, lack comprehensiveness, and are able to serve only a small fraction of persons with developmental disabilities who need long-term habilitation/rehabilitation services, residential options, and other supportive services. Virginia has not accomplished policy development and planning for the delivery of services and assistance which will promote the maximum productivity, independence, and community integration of all persons with developmental disabilities.

There is currently very limited accurate documentation concerning the numbers, characteristics, and unmet service needs of Virginians with developmental disabilities. The lack of such information has resulted in insufficient planning and advocacy to expand services. Since many persons with developmental disabilities do not currently have an active focal agency at either the state or local level, no formal effort is being made to develop a centralized data base on the size and nature of the population with developmental disabilities and the extent to which service needs are met or unmet. There must be systematic identification of this population and accurate formal assessment and documentation of service needs.

RECOMMENDATIONS

- o The General Assembly should require and provide funding for a coordinated statewide data base on disability to be established and maintained. This base of information must include extensive data about the characteristics and service needs of persons with disabilities, detailed information about relevant programs and services provided by state and local agencies, and employment information.

- o The General Assembly should require that all State and Federally-assisted programs in Virginia adopt and uniformly operationalize consistent definitions of services and eligibility criteria for disability programs.

- o The General Assembly should require all State and local agencies which receive public funds to establish and maintain waiting lists of people requesting services who are not being served or who desire additional services to provide data for planning, evaluation, and program development activities.

ISSUE #3 Lack of Sufficient and Appropriate Human Services in Virginia and Interagency Limitations

There are many descriptions in the literature of model and ideal service systems for persons with developmental disabilities. All emphasize that long-term habilitation/rehabilitation services must be comprehensive and community-based, with complementary assisted living and employment options and other support services. Case management is the keystone of such a system so that programs and services may be individualized and accessed.

While expansion of the human service delivery system will be necessary to properly address and meet the needs of persons with developmental disabilities, existing resources in Virginia can also be maximized or modified. For instance, coverage under Virginia's current Medicaid plan is limited and does not take advantage of several Federal options. Case management services and day habilitation services are permissible options that are priority unmet needs for many persons with developmental disabilities. The specific programs and services of state and local human services agencies have not been thoroughly examined to determine and document their current or potential utilization by all persons with developmental disabilities. This includes the Core Services provided by DMHMRSAS and CSBs and services provided by DRS, DVH, and DDHH. Interagency program collaboration and coordination of client services are difficult to achieve because of variations in specific mandates, administrative structure and operations, limited target populations, funding restrictions, and other constraining "turf" issues. The lack of formal case management for most persons with developmental disabilities impedes their accessing services across multiple agencies and programs.

RECOMMENDATIONS

- o The General Assembly should formally determine and enforce the ability and responsibility of all existing State and Federally-assisted agencies and programs to accommodate persons with developmental disabilities with appropriate services and supports. This may require formal interagency agreements initiated and enforced by the Secretary of Health and Human Resources and other cabinet Secretaries.

- o The General Assembly should provide sufficient funding and allocate appropriate manpower to enable significant growth in the human services system in Virginia. New specialized services and supports must be developed, financed, implemented, and monitored to meet the needs of Virginia's unserved/underserved population of persons with developmental disabilities. This may be accomplished both by expansion/modification of existing and traditional programs to accommodate persons with a variety of types of disabilities, and by creation of new appropriate programs and services needed by these constituencies.

ISSUE #4 Lack of Designation and Enforcement of Agency Responsibility for All Persons with Developmental Disabilities

Virginia needs to formally establish and enforce specific agency responsibility for the provision and coordination of comprehensive services for all persons with developmental disabilities, especially those who are not mentally retarded or mentally ill. Agencies must be provided with clear authority and with financial/manpower capacity to appropriately address their responsibilities to provide services and supports for persons with developmental disabilities.

Under current state law in Virginia, all disability constituencies are addressed, at least theoretically, within the authority and mandates of one or more state agencies for the provision of some level of services. The responsibilities of DMHMRSAS, DVH, and DDHH towards specific constituencies are quite explicit, although certainly not equivalent. Much more vague is the recent designation in 1989 of DRS as the state agency responsible for "coordinating rehabilitative services to persons with functional and central nervous system disabilities." DRS also received a legislative mandate and funding to initiate and conduct a small pilot program of "long-term rehabilitative case management" for persons with functional and central nervous system disabilities. DRS must now define its role and focus in the development of an array of vocational and non-vocational services appropriate for persons with severe and chronic disabilities.

RECOMMENDATIONS

- o The Secretary of Health and Human Resources and the Board for Rights of the Disabled should identify and address through the PLAN OF COOPERATION the service needs of constituencies with developmental disabilities who are currently unserved/underserved.

- o The General Assembly should authorize and provide funding for a legislative study to determine the agency/agencies responsible in Virginia to provide/coordinate comprehensive services for **all persons with developmental disabilities**, based upon the federal definition in the Developmental Disabilities Act.

- o The General Assembly should provide the Department of Rehabilitative Services with adequate funding/manpower to operationalize its legislative status as the state agency responsible to provide/coordinate services for persons with functional and central nervous system disabilities. This should coincide with the legislative mandate and funding for DRS to initiate and conduct a small pilot program of long-term rehabilitative case management services for persons with functional and central nervous system disabilities.

ISSUE #5 Inadequate Funding

Services for persons with developmental disabilities are frequently expensive. Their unique and highly individualized characteristics generally require programs with intensive services and staffing. Except for the budgets of DMHMRSAS and CSBs, there is very limited dedicated funding in Virginia for services for persons with developmental disabilities. These resources are not available to persons with developmental disabilities who are not mentally disabled. Limited direct assistance is available to persons with sensory impairments through DVH and DDHH. DRS can provide only limited vocational rehabilitation services and independent living rehabilitation services to persons with developmental disabilities. Personal and third party financial resources are seldom available or sufficient to purchase the long-term habilitation/rehabilitation, housing, and community supports they need. There is no question that establishing and maintaining the appropriate spectrum of services and assistance needed by the large and varied population of persons with developmental disabilities will greatly exceed the current financial and manpower capacity of the human services system in Virginia. That capacity must be expanded.

Despite the fact that it is both cost effective and humane to provide services to persons with disabilities that will increase their productivity, independence, and integration into community life, it is difficult to generate significant new revenue and resources to increase and establish new human services. There is also heavy competition for public funding among various disability populations and other disadvantaged groups. Clearly, there must be aggressive legislative advocacy to establish funding for the maintenance and expansion of services and supports for all persons with developmental disabilities. Innovative revenue sources specifically for this purpose should be explored and developed. It must be recognized that future funding growth and service expansion must have a dual focus. It must continue to address current documented unmet needs and waiting lists and it must address the probable growth in demand for services as other individuals with developmental disabilities become identified and determined eligible for services.

RECOMMENDATIONS

- o The General Assembly should provide sufficient funding and allocate appropriate manpower to enable significant growth in the human services system in Virginia. New specialized services and supports must be developed, financed, implemented, and monitored to meet the needs of Virginia's unserved/underserved population of persons with developmental disabilities. This may be accomplished both by expansion/modification of existing and traditional programs to accommodate persons with a variety of types of disabilities, and by creation of new appropriate programs and services needed by these constituencies.

- o The General Assembly should provide the Department of Rehabilitative Services with adequate funding/manpower to operationalize its legislative status as the state agency responsible to provide/coordinate services for persons with functional and central nervous system disabilities. This should coincide with the legislative mandate and funding for DRS to initiate and conduct a small pilot program of long-term rehabilitative case management services for persons with functional and central nervous system disabilities.

SECTION VIII

**IMPLEMENTATION AND ADVOCACY PLANS
FOR THE BOARD FOR RIGHTS OF THE DISABLED**

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IMPLEMENTATION AND ADVOCACY PLANS FOR THE BOARD FOR RIGHTS OF THE DISABLED

The **1990 REPORT** and accompanying documents provide an overview of Virginia's present status, along with recommendations for actions which would promote full independence, productivity and community integration for all Virginians with developmental disabilities. The recommendations offer hope, specific direction, and some new consumer-directed ideas for maximizing the potential and improving the quality of life for persons with developmental disabilities. The goal of this section is to outline and discuss the implementation of the **1990 REPORT** Recommendations. This critical piece of the **1990 REPORT** will ensure that the work done to date can be further developed to have even greater impact on the lives of Virginians with developmental disabilities and their families.

It is important to remember that many of the **1990 REPORT** Recommendations are long term, "systems change" initiatives that can not occur overnight. The strategies proposed in this section incorporate a multi-tiered approach, including short and long range objectives. Traditional activities like interagency training and public education, as well as innovative approaches such as coalition building with non-disability related groups and media campaigns, are necessary. While strengthening grassroots support from both the disability and non-disability communities, the focus must also be to influence elected and appointed officials, including state agency heads and staff.

To date, there have been many previous recommendations, mandates, reports, conferences, etc. concerning the needs of persons with disabilities. The **1990 REPORT** Recommendations are the product of input received from many of these forums. These recommendations and this plan for implementation have two overarching goals:

- to consolidate many of the disparate mandates and activities of the past; and
- to build a unified coalition of individuals and organizations prepared to advocate for and experience true independence, productivity, and community integration for persons with developmental disabilities.

PHASE I: January - June, 1990

The first step is to move the recommendations from theory to reality. The initial task of the Board for Rights of the Disabled will be to identify specific strategies and action steps for each of the **1990 REPORT** Recommendations. Each BRD Committee (Education, Employment, Health, Housing, Transportation, and Planning) will be responsible for addressing and monitoring relevant recommendations. Strategies and action steps will be developed. Appropriate state agencies and consumer groups will be requested to take the lead on designated actions steps. As members on the Board for Rights of the Disabled, eight agency heads will have a dual responsibility to advocate for the rights of persons with disabilities and to ensure implementation of **1990 REPORT RECOMMENDATIONS** pertinent to their agency.

It is estimated that this task will be completed and presented to the full Board for Rights of the Disabled by July of 1990, and shall be monitored by the BRD Steering Committee. Follow through will be initiated through direct correspondence from BRD to the **PLAN OF COOPERATION (BRD Steering Committee, January - July, 1990)**

PLAN OF COOPERATION

The Virginia State Code, 51.01-1 establishes the PLAN OF COOPERATION wherein twelve agencies which serve persons with disabilities shall formulate a plan to promote the fair and efficient provision of rehabilitative and other services to persons with disabilities. Currently, the Secretary of Health and Human Resources is the Chairperson of the PLAN OF COOPERATION. Although it is currently unknown if that will be continued during the next administration, ongoing interaction with him/her, as well as with Secretaries of Economic Development, Education, Transportation, and Public Safety, will be necessary to gain their support for the realization of our goals.

Representatives of the Board for Rights of the Disabled shall make a series of presentations on the **1990 REPORT** to the policy makers and staff members of the PLAN OF COOPERATION (March - July, 1990). These meetings will provide BRD with access to the key players who are not only in the position to support the **1990 REPORT** Recommendations, but more importantly, to influence their implementation. Eight of the twelve members of the Plan of Cooperation have a dual role in this process, as an agency head and as a full member of the Board for Rights of the Disabled. These presentations will lead to the next step of making additional presentations to other related agency boards and committees. This process has recently proved to be an effective method of conveying the recommendations of the 1988-90 BIENNIAL REPORT. (**Steering Committee, March - October, 1990**)

The crucial piece of this step will be the follow-up. A letter will be sent to agency heads specifically addressing recommendations relevant to their agencies and requesting a response regarding action and implementation. Action based on these responses will be monitored by the BRD Steering Committee. Reports from the PLAN OF COOPERATION Development Committee will be requested by BRD for their July 1990 and January 1991 meetings in order to further monitor these actions.

Another activity of the PLAN OF COOPERATION, relevant to this implementation plan, is the development of a guide to publically supported services available in Virginia for persons with disabilities. Determining what services are available from which agencies, and how they all fit together is confusing to both consumers and professionals. There are many entitlements, programs, and services that are available to persons with disabilities. They originate in six different Federal agencies and are administered by many more State and local agencies, as detailed in the **1990 REPORT, APPENDIX A, "REPORT OF FINDINGS FROM THE ANALYSIS OF FEDERALLY-ASSISTED AND STATE FUNDED PROGRAMS SERVING INDIVIDUALS WITH DEVELOPMENTAL DISABILITIES IN VIRGINIA."** Through the guide of services being produced by the PLAN OF COOPERATION, members of the Board for Rights of the Disabled can be better informed of the supply, demand, and accessibility of services and can plan its policy agenda accordingly.

RELATED ACTIVITIES

DD Grant Projects

Another strategy will be for the Board for Rights of the Disabled to utilize the **1990 REPORT** Recommendations in determining the specific funding targets for DD Grant projects, beginning with the Federal Year 1991 funding cycle. Since these recommendations originated from consumer input, consumers will now be able, through specific grant projects, to implement and fulfill the recommendations that they formulated. Thus, the DD Grant projects can concretely focus on consumer-generated needs and actively work towards the visions and the goals put forth in the **1990 REPORT**. The status of relevant DD Grant projects will be monitored quarterly by BRD Committees.

State Plans

One of the responsibilities of the Board for Rights of the Disabled is to review drafts of state agency plans. The recommendations from the **1990 REPORT** will provide a structure for this evaluation. The plans can be monitored in light of their promotion of the criteria of independence, productivity, and community integration, thus building in a system of accountability. **(Planning Committee, ongoing)**

Study Commissions

The **1990 REPORT** Recommendations and the applicable information found throughout the Report will be presented to appropriate study commissions for their review and inclusion. This will entail staff of the Board for Rights of the Disabled determining the appropriate staff contacts and presenting applicable material from the **1990 REPORT** to these commissions. **(April -December, 1990)**

PHASE II: June, 1990 - October, 1991

After operationalizing the **1990 REPORT** Recommendations, the Board for Rights of the Disabled must begin enhancing, broadening and unifying the grassroots support for disability issues. In this phase of implementation, the BRD will:

- **Provide education to the general public** through presentations, DD Grant projects, awareness days, public service announcements on radio and television, newspaper and magazine feature stories, press conferences, and extensive awareness activities in the schools;
- **Provide education to targeted non-traditional groups whose goals are parallel to those of disability advocacy groups** (e.g. support needs of persons who are elderly are similar to those of persons with developmental disabilities, furniture movers desire building ramps and wide doorways as do persons who use wheelchairs) and mobilizing these groups for action;
- **Encourage and provide opportunities for an alliance** between the multitude of disability advocacy and support groups in the Commonwealth;
- **Encourage the above groups to participate in a letter writing and telephone campaign and public forums** to inform elected officials of their beliefs in independence, productivity and integration and any relevant legislation that would support these goals.

During the beginning of Phase II, the BRD staff will request to meet with each agency's planning staff to begin efforts to formulate cost/benefit analyses of their services and to specify the information needed for a statewide data base. The resulting information and economic analyses will ultimately be presented as hard evidence, rather than subjective requests, to the public in the above detailed public education campaign. The information will ultimately be submitted to the General Assembly in 1991/1992 as support for legislative actions which respond to the **1990 REPORT** Recommendations.

The state mandated BIENNIAL REPORT of the Board for Rights of the Disabled which focuses on all disability concerns, will be linked to the **1990 REPORT** Recommendations and will serve as another avenue to promote the **1990 REPORT** Agenda. The Biennial Report will identify and track the cost/benefit analyses of services to persons with disabilities including the success of state agencies in meeting the identified needs. Again, this information will be a powerful tool in showing policy makers the economic benefit behind the recommendations.

One of the most crucial groups to reach for the advancement of our goals is elected officials. Introductory letters and copies of the **1990 REPORT** will be sent to all members of the General Assembly, Virginia's Congressional delegation and their respective staff. It will then be necessary to arrange a series of meetings to discuss the content. The initial meeting will be with the Governor and the principal Secretaries (Economic Development, Health and Human Resources, Education, Transportation and Public Safety). This strategy will also provide a forum to discuss additional plans to advance the recommendations and the goals of independence, integration and productivity. **(March - October, 1990)**

On the Federal level, meetings will also be requested for members of BRD, accompanied by the Secretary of Health and Human Resources, with the Congressional delegation to provide them with an overview of the **1990 REPORT** and how they can take action to promote the goals and recommendations. **(May - October, 1990)**

On the state level, it will be necessary for BRD members to meet with members of the General Assembly and appropriate staff to petition their assistance in advancing the legislation needed to achieve the independence, integration, and productivity of Virginians with disabilities.

Advocacy efforts are important and need to be ongoing on many levels. Therefore, the Board for Rights of the Disabled will request to convene a Governor's Conference on Disability. The conference will provide a forum not only to educate elected and appointed officials about the abilities of persons with disabilities, but also to re-enforce the need for implementation of the **1990 REPORT** Recommendations. This conference will also demonstrate consumer empowerment and self-advocacy for the legislators. Information and supporting facts will be presented by persons with disabilities. This conference will culminate in a citizens rally to show the true broad based support from the disabled and non-disabled communities for the goals of independence, productivity and integration. **(special conference committee - begin planning March, 1990; actual conference in October, 1991)**

PHASE III: April 1991 - March 1992

The activities of this phase must be based on what has occurred during the first two phases. In August of 1992, the next **THREE YEAR DEVELOPMENTAL DISABILITIES STATE PLAN** must be submitted. This phase presents the opportune time to step back and evaluate what has worked and what we have learned, and to modify our plans accordingly. As this implementation plan is being formulated, there are still many unknowns which could significantly impact not only the attitudes of elected and appointed officials who will be making policy decisions, but also on the actual procedures we must follow. Thus, this implementation plan will naturally lead into the next step, our **THREE YEAR DEVELOPMENTAL DISABILITIES STATE PLAN FOR FEDERAL YEARS 1992-94.**

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